THE MAKING OF THE UNBORN PATIENT:
Medical Work and the Politics of Reproduction in Experimental Fetal Surgery, 1963-1993

by

Monica J. Casper

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

Sociology

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA

San Francisco

For my parents

Patricia and Dennis Struck

for their love, support, and encouragement

and

In loving memory of my grandfather

Earl Hans Christensen

the first "sociologist" in my life

Acknowledgments

I wrote this dissertation during a particularly difficult year and could not have finished it without the support of many people. First and foremost, this dissertation is dedicated to my parents, Patricia and Dennis Struck, for always being there and for making me believe I could do anything. I would not have made it through college and graduate school, rigorous experiences both, without their encouragement. Their love, wisdom, and humor are remarkable gifts which have shaped my life.

This dissertation is also dedicated to the memory of my grandfather, Earl Hans Christensen, the first "sociologist" I ever knew. Gramps possessed an incredible zest for knowledge and curiosity about the world which he imparted to me and my sister. His favorite social critique, that religion is the opiate of the people, was my first exposure to Karl Marx. Sadly, Gramps died of cancer in 1990, one month before I moved to San Francisco to begin graduate school. He was proud of his granddaughter, "the scholar," and would have relished my completion of this dissertation.

Ross Smith once chose the right seat on an airplane and changed the course of our lives. I am thankful each day for his humor and passion, for his intellectual curiosity, and for reminding me that the natural world is a wondrous place. As a sometimes worn-out participant in what Weber called the "mad hazard" of academia, I am blessed to have such a vibrant and patient partner to sustain me.

My dissertation committee deserves a tremendous amount of gratitude. Adele Clarke has been a fabulous mentor, providing encouragement, feedback, advice, support, and criticism beyond the call of duty. As Chair of my committee, the final shape of this dissertation owes much to her careful editing, analytical prodding, and thoughtful critiques. Virginia Olesen, who has taught me a great deal about qualitative methods and women's health, is just the kind of engaged, ethical, and passionate scholar I hope to be. Anselm Strauss, my intellectual "grandfather," is a

steady source of inspiration. So, too, is Donna Haraway, who has provided important and challenging feedback on many aspects of my work and whose own work in feminist technoscience studies is an intellectual beacon.

Joe Cocker once sang that he could get by with a little help from his friends, a sentiment I heartily share. Matt Kling provided the kind of loving support (and computer assistance) that most graduate students only dream of. The existence of this dissertation is due in no small part to his belief in me. Tanya Casper is, without a doubt, the best big sister in the world. Loyal, protective, and sarcastically funny, she has been my ally and sounding board during some of the past year's most difficult moments. Marc Berg has been a constant source of support, encouragement, and criticism. I am grateful for the scholarly acumen he brings to our relationship and for the many inspiring ways he challenges me to sharpen my intellectual skills. Lisa Jean Moore and Mike Curtis, my dissertation writing group, have offered thorough, challenging, and invaluable criticisms and suggestions. Both Lisa and Mike have enriched my life with their generous friendship, steadfast support, and lively minds. They have also made graduate school not only bearable, but even--gasp!--fun sometimes. Linda Hogle, Debora Bone, Margi Stuart, Lynn Morgan, Stefan Timmermans, Jon Guice, Joe Dumit, Barbara Koenig, Karen Linkins, A.J. Alejano, and Kit McGinniss have contributed to this dissertation and my sanity in more ways than they probably realize. A special thanks to the many friends and colleagues who kept reminding me that the only perfect dissertation is a done dissertation.

I am also deeply grateful to my many informants for opening their homes and workplaces to my scrutiny. In New Zealand, Margaret Liley, Stephanie Liley, Bill Liley, Jr., Graham Liggins, Ross Howie, Florence Fraser, Pat McCarthy, and David Becroft were all extremely gracious, forthcoming, and helpful. I am especially grateful to Margaret Liley for making me feel welcome on her beautiful farm in Taumarunui and for patiently answering all of my probing questions about her late husband. Val

Corcoran, Kevin Townend, and Helen Hopman at National Women's Hospital provided helpful organizational and logistical support. Karliss Adamsons and Arsenio Comas in Puerto Rico and Vincent Freda in New York brought the experimental work of the 1960s vividly to life for me. I am extremely grateful to the clinical and administrative staff of the Fetal Treatment Unit at Hilltop Hospital for sharing their experiences and insights with me. They may not agree with my interpretation of their work, but their input has substantially shaped this dissertation. A large thanks must also go to the patients and their families who shared their stories with me.

Although the life of a graduate student is often a poor one, I have been generously funded by the University of California, San Francisco, through a Regents Fellowship, a Tuition Scholarship, and a Graduate Division Fellowship. A School of Nursing Century Award and a Graduate Student Research Award provided an important source of funding during the final stages of research. I was also honored to receive a University of California President's Research Fellowship in the Humanities. A Doctoral Dissertation Improvement Grant from the National Science Foundation (#SBR-9320173) made possible my research trips to New Zealand and Puerto Rico, for which I am very grateful.

Portions of Chapter 2 were previously published in Casper, Monica J. 1994. "At the Margins of Humanity: Fetal Positions in Science and Medicine." *Science, Technology, and Human Values*, 19(3):307-323.

Abstract

THE MAKING OF THE UNBORN PATIENT:
Medical Work and the Politics of Reproduction
in Experimental Fetal Surgery, 1963-1993

Monica J. Casper

This dissertation examines the historical emergence of experimental fetal surgery. In 1963, Liley pioneered intrauterine transfusions, allowing direct treatment of an impaired fetus and ushering in the era of the fetal patient. Two decades later, surgeons at Hilltop Hospital breached the womb even more profoundly. They removed a 21-week old fetus from its mother's uterus, operated on it surgically, and replaced it for subsequent delivery by cesarean section. These events represent a culmination of several decades of clinical research. Historically, experimental fetal surgery has been the site of rich and varied intersections of medicine, science, technology, and cultural politics. It has also been a contested domain within which participants have collectively created a new social and medical category: the unborn patient.

This analysis of fetal surgery explores the interrelated themes of medical work and reproductive politics. I examine how work practices in fetal surgery are organized around fetal and maternal work objects both inside and outside the operating room. The medical work required to transform fetuses into patients has been shaped by reproductive politics both in the U.S. and in key historical locations such as New Zealand and Puerto Rico. Simultaneously, medical recognition of the fetal patient seeps out of the operating room and into the cultural sphere. Experimental fetal surgery is thus a contested practice which affects the broader domain of reproductive health. Fetal surgery has a number of major implications for pregnant women's health, including surgical complications, post-operative management, and potential long-term sequelae. A key goal of this dissertation research is to reframe fetal surgery as a women's health issue rather than a pediatric concern.

This research draws on a variety of data sources including interviews, ethnography, historical research, scientific and clinical literature, videos, and popular culture. Data were analyzed using qualitative methodologies, especially grounded theory. Themes include a theory of work objects, historical emergence of fetal surgery, intersections of medicine, science, and technology, the heterogeneous domain of fetal surgery, and pregnant women's experiences.

Table of Contents

Chapter 3
Breaching the Womb:
Historical Emergence of the Fetal Surgical Patient
84

Chapter 4
A Hybrid Clinical Practice:
Intersections of Medicine, Science, and Technology in Fetal Surgery
145

Chapter 1

INTRODUCTION

"Treatment of the unborn has had a long and painstaking gestation; the date of confinement is still questionable; and viability is still uncertain. But there is promise that the fetus may become a 'born-again' patient."
(Harrison 1991a:7)

"Who speaks for the fetus?"
(Haraway 1992:312)

Setting the Scene

Imagine a busy operating room filled with fifteen or more medical staff, all in scrubs. The room is hot, noisy, and vibrating with energy. On the operating table, surrounded by gowned and masked figures, lies a pregnant woman. Her eyes are taped shut, she is catheterized and intubated, and she looks very much like any surgical patient. In close proximity to the operating table are a number of technologies, including monitors, anesthetic tanks, and surgical instruments. After the woman has been anesthetized, a team of surgeons slices her abdomen, peels back its layers, and clamps it open with large silver clips. Her uterus and amniotic sac are then surgically opened and the amniotic fluid is drained, exposing the fetus within. The fetus is partially removed from the woman's uterus and an incision is made in its chest, inside of which is placed a telemetric monitoring device. The surgeons then make additional incisions in the fetal body and surgically "fix" the unborn patient's defective and/or misplaced organs. When the surgeons have completed their work, they close the fetal incisions, replace the fetus within the amniotic sac along with saline solution, and reseal the woman's uterus and abdomen. If surgery has been successful, the fetus will be delivered by cesarean section when it reaches term. Depending on gestational age at the time of surgery, it may or may not have scars. If

the surgery proves unsuccessful, the fetus will most likely die during the operation or in utero. In either case, the pregnant woman now faces several weeks of intensive monitoring and management by the medical staff.

Is this a science fiction story or the facts of life on the eve of the twenty-first century? The above account is a composite description of fetal surgery based on my observations of many such surgeries, not on *Star Trek* but performed on real pregnant women and their fetuses in an actual operating room. Yet certainly fetal surgery contains elements which suggest science fiction and its seemingly boundless possibilities: fetal surgeons going where no man has gone before; the womb as the final frontier in medicine; fetal patients who/which heal without scars.[1] Experimental fetal surgery is phantasmic and fascinating precisely because it transgresses a number of extant yet shifting biomedical and cultural boundaries. It challenges what we ostensibly know as the limits and borders of pregnant female bodies, usually hidden fetal bodies, maternal/fetal relationships, "modern" health care, medical technologies, the margins of life, and what counts as human or person in the late twentieth century.

The story of experimental fetal surgery is clearly about biomedicine and the meanings associated with health and disease in the United States at this particular historical moment. In this story, brave and talented surgeons, heroic and self-sacrificing mothers, and tiny, ailing fetuses are brought together in bright, hot operating rooms to fulfill techno-dreams of medical progress. Yet there is another version of the story that extends beyond the operating room, to the cultural milieu which cradles and seeps into biomedical work. In this respect, experimental fetal surgery embodies how we think about reproduction, pregnant bodies and, most of all, those tiny, dependent occupants of women's uteri--fetuses. Fetal surgery is about

---

[1]In this dissertation I take seriously the politics of discourse, preferring to discuss fetuses in non-personal terms. I do this both to counter political activities which assert fetal humanity and to illustrate that fetal personhood is contested and ambiguous. Throughout this dissertation, with the exception of informants' own words, I opt to use "which" instead of "who" when speaking of fetuses.

investing in fetuses, not only in terms of spending contested health care resources on behalf of fetal patients, but also through the social and cultural construction of certain types and classes of fetuses as worthy of investment. As such, fetal surgery is intimately connected to other fetal practices in which fetal personhood and worth are salient ontological battlegrounds, especially abortion politics.

This dissertation, then, is about the ways in which some fetuses in the U.S. are *invested in* medically and technologically, reflecting also economic, political, religious, and cultural investments. But there is an important difference in thinking about fetuses that is less salient regarding infants and children. Human fetuses are not simply like infants and children, only younger. Rather, fetuses exist within and are *fully dependent upon* pregnant women's bodies. Thus, to talk about fetuses in any meaningful way we must also talk seriously about pregnant women and reproductive politics. For every investment made in fetuses, even by women themselves, there is a corresponding consequence or implication for the pregnant women in whose bodies fetuses live. My account is, in part, designed to re-locate pregnant women as participants in fetal practices and to articulate some implications of these practices for and within women's lives. Indeed, a key goal of this dissertation is to reframe fetal surgery as a women's health issue rather than a pediatric concern. The story of fetal surgery presented here, then, is about the biomedical work that takes place within the operating room and laboratory, as well as the objects of that work--pregnant women and fetuses--and how they are conceptualized culturally and politically.

What, exactly, do I mean by the term *investment*? In her profoundly moving analysis of life and death in northeast Brazil, Scheper-Hughes (1992) discusses infant mortality and the meanings of "child death" and "mother love" within a cultural context of extreme poverty and despair.[2] This work is immensely helpful in understanding

---

[2]Scheper-Hughes attempts to convey, in Brazilian women's own voices, the cultural production of indifference to child death among the poorest poor in shantytowns and *mocambos* surrounding major urban areas such as São Paulo. She asks important questions about this particular cultural context: What are acceptable levels of infant and child death? How does bureaucratic indifference to such deaths feed

fetal investments across different national contexts. The U.S. situation in which fetal surgery has germinated embodies characteristics opposite to the Brazilian context discussed in Scheper-Hughes' account. I would suggest that if Brazil is a context in which *many* infants and children are *not* invested in, the U.S. is a context in which at least *some* infants and children are objects of heavy investment. Here, there is intense capital investment in (some) fetal and neonatal patients through massive expenditures of health care dollars on high-tech treatments. Further, fetuses have also, within the past decade, become investments both culturally and economically. Fetuses and neonates have become labor-intensive objects not only of medical and scientific work, but also of political activism, cultural production and dissemination, and a host of other social practices.

As Petchesky (1987:61) argues, the fetus has become a "public presence" which "has acquired a symbolic import that condenses within it a series of losses--from sexual innocence to compliant women to American imperial might. It is not the image of a baby at all but of a tiny man, a homunculus." In short, the fetus has become an American icon on all fronts. A number of questions related to investment may be generated about fetal surgery's existence within a political context in which fetuses

---

into maternal indifference? How is maternal indifference to medical diagnoses of children manufactured? How is it that the violent yet often slow and agonizing deaths of millions of infants and children are made sense of by women and the wider community? Scheper-Hughes describes for us a culture in which the smallest humans--infants and children--are forsaken in a world of deprivation; they are neither fed adequately nor protected from scourge and disease. In short, they are not *invested in* by Brazilian society in any meaningful way. Women bear witness to their children's deaths, but do so through a culturally induced indifference to suffering.

In a similar vein, Kertzer (1993) has presented a stunning analysis of infant abandonment in eighteenth- and nineteenth-century Italy. He argues that hundreds of thousands of women, many of them unmarried, were forced by the Catholic Church and local officials to abandon their babies as foundlings in order to "save" their own honor. He notes, however, that men, particularly married and/or propertied men, were also protected within this system of abandonment by removing the evidence of their sexual activities--namely, the babies. What Kertzer, like Scheper-Hughes, describes is a social, political, and religious context in which women's maternal practices were shaped in many ways, with often devastating consequences. The women may have been left with honor, but they lost their infants to abandonment and usually death and many, especially immigrant women and those with no family support, were also prosecuted for infanticide. Echoing Scheper-Hughes discussion of "mother love," Kertzer (1993:178) argues that in the industrializing cities of northern Italy, "we find a culture in which small children's welfare was not parents' greatest priority. Large-scale abandonment of legitimate babies could only occur in a culture which--at least by today's standards--played down the mother-infant bond and invested little emotion in relations with small children."

are so highly charged. Who invests in which fetuses? Why? In whose or what interests? How do fetuses become objects of biomedical and scientific work, political work, and cultural production? How is the fetus defined as a cultural repository, political symbol, or biomedical object? Who represents or speaks for fetuses? How is our national obsession with medical diagnosis applied to fetuses? What does "mother love" (Scheper-Hughes 1992) look like in certain strata of the U.S., a context of relative abundance compared to many other nations? And what is the opposite of indifference to child death? These questions allow us to examine fetal surgery by refracting it through a critical lens in which its content and context are made problematic.

Despite the graphic and "reproductive" nature of experimental fetal surgery, I have often been asked what this practice has to do with gender or with abortion politics. It is a strange sort of question given that in the U.S., fetuses are perhaps the most contested of human biological objects.[3] Rather than despair because these connections are not immediately obvious, I have taken such queries as a sociological challenge. As a disciplinary practice, sociology is about analyzing the many connections which constitute social life--connections among people, among institutions, between people and institutions, between culture and politics. These connections make up what Park (1952) called the "big picture" of social life. This dissertation seeks to articulate and make visible the often hidden connections

---

[3] It should come as little surprise that fetal surgery, which constructs fetuses as patients and tiny persons worthy of investment, is welcomed by anti-abortion activists. Such connections suggest that we should query the lengths to which people and groups will go on behalf of fetuses. For example, those who seek to protect and speak for the fetus number among their ranks so-called Christian terrorists engaged in violent, often lethal assaults against abortion providers. Since I began this project, "pro-life" terrorists have murdered abortion providers and clinic workers and bombed a number of abortion clinics across the U.S. In March 1993, Dr. David Gunn, an abortion provider at Pensacola Women's Medical Services in Florida, was shot and killed by Michael Griffin, an anti-abortion zealot. In 1994, Dr. John Britton and his security escort, James Barrett, were murdered by Paul Hill outside of the Ladies Center, also in Pensacola. June Barrett, also an escort, was wounded in the assault which killed her husband. On December 30, 1994, anti-abortion terrorist John Salvi went on a shooting rampage at an abortion clinic in Norfolk County, Massachusetts, wounding five people and killing two clinic workers, Shannon Lowney and Lee Ann Nichols. Salvi, 23 years old, was recently found to be competent to stand trial for the murders (Associated Press 1995).

between and among the many different elements in fetal surgery. The "cutting-edge" practice of fetal surgery is simultaneously about medical and technoscientific work, the cultural politics of reproduction, representations of fetuses and pregnant women, and the pregnant women and fetuses themselves. It is my task to clarify how these connections are omnipresent, real, and consequential.

A quick word before moving on about the title of my dissertation, which is ironic but perhaps not obviously so. The major fetal surgery text, now in its second edition, is entitled *The Unborn Patient: Prenatal Diagnosis and Treatment.*[4] This influential volume lays out the history of fetal treatment, current approaches, physiological foundations of clinical practice, and possible future treatments. In short, it is a clinical manifesto of sorts for the emergent specialty of fetal surgery. The title of this dissertation, *The Making of the Unborn Patient*, is meant to be a critical and ironic play on this popular medical text. This dissertation provides a behind-the-scenes look at fetal surgery and the work required to create unborn patients, including the production of accepted disciplinary texts and professional socialization materials.

In the remainder of this introduction I do several things. I first discuss what fetal surgery is, who the relevant actors are, and its social organization as an emergent biomedical specialty. I then address the second part of my dissertation title, medical work and the politics of reproduction, which together have permeated and shaped experimental fetal surgery in significant ways. I review theoretical perspectives on work in medical sociology and social studies of science and technology, and then discuss feminist research on reproduction and nascent perspectives on social and cultural constructions of fetuses. This discussion paves the way for analysis in later chapters in which I argue that fetal surgery is characterized by the intersection of medical work and its objects with the politics of

---

[4]See Harrison, Golbus et al. (1991).

reproduction. In closing, I discuss what this dissertation will *not* do and provide a brief overview of each chapter.

Locating Experimental Fetal Surgery as Practice and Politic

In 1981, surgeons in California removed a 21-week old fetus from its mother's womb, operated on it surgically, and replaced it for subsequent delivery by cesarean section. Media accounts of this surgical feat characterized it as a "bold operation" and a "dramatic new enterprise," and the fetus was described in terms ranging from "unborn child" to "miracle baby."[5] Although the baby, named after the head surgeon, died shortly after birth, this operation marked the beginning of more than a decade of clinical experience with fetal surgery.

Accounts of the 1981 fetal surgery in San Francisco parallel media accounts of an earlier fetal operation in the South Pacific in 1963. Dr. William Liley, considered by many to be the "father" of fetal surgery (Green 1986; Harrison 1991a), pioneered fetal transfusion technology at National Women's Hospital in Auckland, New Zealand. Fetal transfusions were designed to save fetuses, and sometimes their mothers, from hemolytic disease and possible death resulting from Rh incompatibility. The first "successfully" transfused fetus was Liley's fourth attempt at prenatal transfusion. The news of this amazing medical success story, and of the fetal patient on which it was performed, was heralded across the globe. Grant Liley McLeod of Hawke's Bay, also named after his medical savior, was described as "the most famous baby in New Zealand" and entered the pages of medical history.

These stories, separated temporally by two decades and geographically by the Pacific Ocean, are nevertheless linked in important ways. Fetal research done in the 1960s in New Zealand, Puerto Rico, and the U.S. paved the way for the headline-making activities of the 1980s. These efforts marked a particularly compelling moment

---

[5]See Saltus (1981) and Cadoff (1994).

in the historical emergence of the fetal patient, a process begun in the 1930s with the administration of penicillin to pregnant women with syphilis and expanded in the 1960s with attempts to surgically treat fetuses in utero. A number of elements of this work have been consistent across time, including the objects of that work and the political context in which it is accomplished. The history of fetal surgery is explored at length in Chapter 3.

Since the 1930s, pharmacological intervention has remained a staple in the fetal treatment arsenal for problems ranging from biochemical defects to premature labor (Schulman and Evans 1991). Other fetal therapies include nutritional supplements for fetal growth and development (Harding and Charlton 1991); fetal blood sampling (FBS), also called percutaneous umbilical blood sampling (PUBS), for treatment of Rh incompatibility, chronic maternal/fetal hemorrhage, infections, and other problems (Moise 1993); selective termination of a "defective" fetus, particularly when there is more than one fetus per pregnancy;[6] the use of corticosteroids in preventing respiratory distress syndrome in premature infants and in facilitating fetal growth and development; the use of catheters and other needles to drain fluids from malformed fetal organs, such as blocked urinary tracts (Harrison and Filly 1991); and many other forms of fetal treatment. Fetal surgery itself is used to treat a variety of structural defects diagnosable by ultrasound, including congenital diaphragmatic hernia, sacrococcygeal teratoma, chylothorax, hydronephrosis, cystic adenomatoid malformation, and urinary tract obstructions.[7]

---

[6]"Selective termination" is a medical euphemism for abortion. I suspect that physicians use this sanitized term to avoid the sticky political and emotional connotations of the word abortion.

[7]Congenital diaphragmatic hernia (CDH) is a condition in which there is a hole in the diaphragm, causing fetal organs to migrate upward into the chest cavity and to impair lung development. Fetal surgery for CDH is designed to repair the diaphragm *in utero* and reposition the organs in the fetal abdominal cavity, thereby making room for subsequent lung development. Many fetuses with CDH die at birth; those who live and undergo surgery after birth generally have respiratory and other problems for the rest of their lives. Sacrococcygeal teratoma refers to a tumor located on both the sacrum, or the part of the vertebrae directly connected to the pelvis, and the coccyx, or the end of the spinal column. Chylothorax is a condition in which there is an accumulation of milky fluid in the pleura, or the serous membrane enveloping the lungs, and lining the walls of the pleural cavity. It usually causes severe respiratory problems. Hydronephrosis refers to an excess build-up of fluid in the kidneys caused by an obstruction to

Potential *future* treatments currently under investigation include gene therapy in utero, in which genes are inserted into a living fetus in order to correct genetic/chromosomal deficiencies (Karson and Anderson 1991); fetus-to-fetus transplantation, in which fetal cells from a dead fetus are transplanted into a living fetus in utero (Crombleholme, Zanjani et al. 1991);[8] and fetal surgery for more complex structural problems such as heart and brain defects. Prenatal genetic therapies are especially touted as the wave of the future given current scientific and economic investments in mapping the Human Genome. One of the selling points of the project has been the claimed downstream biomedical and clinical applications for treating diseases (Kevles and Hood 1992).

Most of these fetal treatment technologies require intervention into fetal bodies *and* maternal bodies. Accessing the fetus always means somehow getting into or through a pregnant woman's body. Yet unlike ultrasound diagnosis, for example, where access is gained exclusively through visual means, access in fetal treatment is physical and material. With pharmacological therapies or nutritional supplements, this may involve something as "low-tech" as a pill or intravenous access. Yet many fetal therapies, especially fetal surgery, require major sustained intrusion into a pregnant woman's body, ranging from catheterization to suction to surgical exposure via cesarean section or hysterotomy. Further, in most fetal treatment cases, with the exception of Rh incompatibility and a handful of other disorders, there is *nothing* physiologically wrong with the pregnant woman. This has significant implications for how pregnant women and their fetuses are perceived both clinically *and* culturally.

---

the flow of urine; untreated, it generally results in renal failure and death. Cystic adenomatoid malformations refer to tumors in the connective tissue surrounding the urinary bladder or gallbladder. Like hydronephrosis, this condition can cause severe kidney damage and/or renal failure. According to one informant, treatment of this condition has been more successful than for any other fetal disease. Urinary tract obstructions, which may be caused by a number of factors, generally result in an excess build-up of fluid in the kidneys, leading to severe kidney damage and/or renal failure. See Harrison, Golbus et al. (1991) for a discussion of other conditions for which fetal treatment has been proposed or is being used.

[8]The claimed advantages of using fetal cells and tissue are discussed in Chapter 2.

The following descriptions of fetal surgery are taken from my fieldnotes and illustrate the material aspects of fetal surgery:

> The surgeons sliced through the woman's abdomen. It was much messier than I thought it would be. There were a number of layers of tissue, fat, muscle, and blood that they had to go through. The incisions weren't neat and clean, either; they would pull the layers apart as they ran a scalpel down the woman's abdomen and the layers would sort of rip apart slowly. As they worked their way through April's body, they would pull parts of the abdomen aside and clamp them with big silver metal clips. After about eight minutes of cutting through her abdomen, they reached the uterus.

At this point in the procedure, the surgeons slice through the uterus and amniotic sac, draining the sac and discarding the amniotic fluid. Once the fetus is exposed, the surgeon places his [sic] hands inside of the uterus to maneuver the fetus. When the fetus is in the desired position, the surgeon removes the body part to be worked on:

> After Dr. Graham pulled the fetus partially out of the uterus, he made two incisions on its left side, one about heart level and one about umbilical cord level in its abdomen. The lower incision was about two fingers wide. After he made both incisions, Graham pushed the organs that had accumulated in the chest cavity back toward their proper place. Immediately, a nurse placed a small device inside the fetus' chest to monitor its condition, while the organs came careening out of the lower incision and hung outside of the fetus' body.

And from another surgery:

> Once Marla was anesthetized, they intubated her orally, taped her nose and eyes, and covered her belly with towels. They then spread her legs apart and inserted a catheter into her vagina, securing it with tape...At 1:40 p.m., the team began swabbing Marla's abdomen with a sterile solution. After a few moments, they began cutting into her abdomen. They sliced through several layers, reached her uterus, and, using ultrasound as a guide, began to cut into it. Continuing to use the ultrasound guidance, each incision proceeded very cautiously. There was a great deal of fluid and what looked, to my untrained eye, like a liver floating around when the uterus was opened. I assumed, correctly, that it was the fetus. Dr. Graham pulled the fetal arm out through the incision, wrapped it in some kind of protective plastic, and attached a monitor to its tiny hand. Marla's uterus was then clamped open with large silver clips. The doctors began to cut into the fetus' upper chest area, inserting a monitor into its chest once an incision was made. They made another, lower incision and the fetal organs became visible.

Both the pregnant woman and her fetus are intensively monitored throughout the surgery via an arsenal of imaging and recording technologies, and the fetus is periodically bathed with a warm solution to simulate amniotic fluid. When the surgeons have completed work on the fetus, they close the fetal incisions, reposition the fetus within the woman's uterus, and fill the amniotic sac with a sterile solution.

Because fetal waste produces and renews amniotic fluid continually, within 24 to 48 hours the sterile solution becomes amniotic fluid. Fetal surgeons then reseal the woman's uterus and abdomen.[9]

It is important to note that fetal surgery is located somewhere along a continuum between experimental protocol and routine medical procedure. As such, studying fetal surgery means taking into account issues such as the history of experimental clinical research, informed consent, connections between physiological research and clinical treatment, and the politics of maternal and fetal research. My dissertation addresses these themes by presenting a portrait or snapshot of several stages of the specialty's development along this continuum. My data reveal significant dynamics that have shaped fetal surgery's emergence as it has unfolded and moved toward institutionalization. The limited scope of fetal surgery, however, means that it is difficult to discuss who is doing it and where it is being done without violating participants' anonymity. (See Appendix A for a fuller discussion of these issues.)

Unlike other fetal treatment practices, which have become ubiquitous, fetal surgery is currently pursued at only a handful of institutions in the U.S. It has also been attempted at a few institutions in the Netherlands, France, Italy, Japan, and the UK. Although I have collected data at many sites, most of my data on contemporary fetal surgery are based on ethnographic research at one major medical center which I call Hilltop Hospital.[10] Although several institutions, both in the U.S. and internationally, have attempted surgical treatments of fetuses, the general feeling is

---

[9]As my fieldnotes illustrate, the fetus is both material and embodied: surgeons must slice through multiple layers of a pregnant woman's body to access their primary work object. Fetal surgical practices are thus comparatively interesting with respect to the proliferation of cultural images which portray the fetus as autonomous, free-floating, and disembodied (Petchesky 1987; Duden 1993).

[10]As a nascent specialty, fetal surgery has been little investigated by sociologists. My data reflect four years of the specialty's growth, especially as it has occurred at Hilltop Hospital. The data do not necessarily reflect what fetal surgery or Hilltop Hospital looks like currently. Thus, while this snapshot of fetal surgery may represent important patterns in the specialty's development during this four-year period, it does not necessarily reflect all of the salient themes and issues which shape fetal surgery *today*.

that other institutions are "waiting to see what happens" (Golbus 1993) with the Fetal Treatment Unit (FTU) at Hilltop. However, many institutions nationally and internationally are actively treating fetuses non-surgically, including pharmacological therapy, routine placement of shunts, and selective termination.

What this means in terms of fetal surgery's entrenchment within the U.S. health care system is that the specialty, although quite institutionalized at one hospital, is not yet fully entrenched elsewhere. This may change, however, as it moves from an experimental procedure to a routine medical practice. Although there is nothing evolutionary or foreordained about this transition, it is nonetheless a goal which many participants in the field hope to achieve. Yet there is serious disagreement within medicine about the future of fetal surgery as a viable specialty. Not all practitioners agree that operating on a fetus still in its mother's womb is good medical practice for a variety of reasons. However, whether or not fetal surgery will endure, other fetal treatments are here to stay. It is important to investigate how pregnant women and their fetuses are conceptualized and treated in both cutting-edge and routine practices, and to ask critical questions about investments in fetal patients and the allocation of health care resources.

Of the available prenatal treatment options, fetal surgery is the most expensive. A single operation can cost thousands of dollars, and every successful fetal surgery requires at least two cesarean sections for the pregnant woman.[11] Patients and their partners must often travel long distances to the hospital and pay for accommodations once they arrive. Given the high cost of fetal surgery, most patients who have gone through the procedure have been middle- to upper-class, insured, white, married women, with a few exceptions. Federal funding of fetal surgery as an

---

[11]Financial data on fetal surgery are difficult to come by. However, a financial counselor at Hilltop Hospital was able to provide information on inpatient and outpatient charges and the total amount paid by patients for 12 operations during a two-year period between July 1990 and February 1992. The least expensive operation was $4,686.30 and the most expensive was $68,884.18. Average cost per operation was $23,562.27. The amount paid by patients (including insurance reimbursement) during this period ranged from $0 to $14,310.20; the average amount paid was $4,368.35.

experimental protocol has provided some opportunity for women of different economic brackets to select fetal surgery, but the majority of patients are those most capable of paying for the treatment themselves. Additional funding to offset patient costs comes from hospital expenditures, as well as from non-profit sources interested in fetal and maternal health such as the March of Dimes. There has been relatively little investigation of economic issues related to fetal treatment,[12] although one cost-benefit analysis (Korenbrot and Gardner 1991:29) found that "fetal therapies that improve birthweight or respiration, reduce major medical problems, or reduce major surgical problems might be cost-efficient in terms of medical expenses alone."

To return to the metaphor of investment, the high cost of invasive fetal treatment coupled with high fetal mortality rates (50+%) and significant maternal morbidity (Longaker, Golbus et al. 1991) suggests that surgical treatment may not be the most effective way to ensure healthy babies and mothers. There are also significant race and class disparities between pregnant women who have access to prenatal care (and which types) and those who do not. For example, Leigh (1994:176) reports that the following groups of women in California usually receive late or no prenatal care: 59 percent of Samoans, 48 percent of Laotians, 47 percent of Cambodians, 32 percent of Vietnamese, and 25 percent of all racial groups combined. In addition, if the current gap in infant mortality rates continues to widen, African American babies will be three times as likely to die as White babies by the year 2000 (Associated Press 1994). These figures beg a serious analysis of the politics of investing in some fetuses at the expense of others.[13] It is within this broader context of the politics of reproduction and a stratified health care delivery system that

---

[12]One reason for this gap in the literature is that fetal treatment is too experimental for a large-scale cost analysis; there is not a large enough patient population to determine average outcomes. However, as Korenbrot and Gardner (1991) argue, one way of evaluating the benefits of fetal surgery is to compare it to neonatal treatment, which is also quite expensive. Benefits might also be operationalized as avoidance of childhood disability, although fetal therapies are at too early a stage of development to assess their impact on chronic childhood diseases.

[13]See Rapp (1993a; 1993c; 1993b; 1994), Rothenberg and Thomson (1994), and Morgan (1995) for a fuller discussion of this issue.

experimental fetal surgery must be analyzed. I now turn to the theoretical underpinnings of this dissertation research.

Investigating Medical and Technoscientific Work

There are a number of ways in which experimental fetal surgery might be investigated sociologically. In tracing the intertwining themes of medical work and the politics of reproduction in fetal surgery, I first focus on the concrete work practices of actors within this domain both historically and contemporarily. The study of work as a social activity is a rich and dynamic tradition in sociological research (Erikson 1990). For example, sociologists have investigated emotion work (Hochschild 1983), invisible work (Daniels 1987; Star 1991), interactional work (Fishman 1978), "people" work (Hughes 1971; Stacey 1984), professional processes and systems (Bucher 1962; Olesen 1973; Freidson 1986, 1994; Abbott 1988; Halpern 1992), and the social organization of work (Becker 1982; Strauss, Fagerhaugh et al. 1985).

I am most interested in the medical and technoscientific work which has gone into building the emergent clinical specialty of fetal surgery. Experimental fetal surgery has been varyingly and simultaneously shaped by the intersections of clinical practice with scientific research, of technologies with female and fetal bodies, of surgeons and clinicians with work objects, and of medical work with the politics of reproduction. In exploring these dynamics, my dissertation draws on and extends perspectives from both medical sociology and social and cultural studies of science and technology. I use the particular local domain of fetal surgery to address broader theoretical questions about work and how it is accomplished in medical and scientific settings.

Perspectives in Medical Sociology

Within medical sociology, perspectives on work have tended to emphasize several themes: the social organization of medical work; studies of professional elites; development of, and conflict between, medical specialties; the nature of experimental clinical practice; and the emergence of new categories of patients. Because my research is situated within the tradition of symbolic interactionism, I draw largely on interactionist contributions to understanding medical work. Interactionist perspectives on work reflect several theoretical assumptions and roots, including the primacy of human action, understanding of selves as social, an emphasis on process rather than structure, anti-determinism, partiality of perspectives, and a commitment to realities as socially constructed.

In attempting to understand the nature of medical and scientific work, I have found it useful to conceptualize such work as meso-level social action. As Hall (1987:19) argues, "the meso domain, with its view of structure as condition and structure as process, constitutes the central arena of sociological analysis because it attends to context, process, and action simultaneously." Viewing work as a form of social action allows for conceptualizations of meaning and agency (Strauss, Fagerhaugh et al. 1985), critical for understanding practices such as fetal surgery which involve an array of heterogeneous actors. Further, because work is often performed within collective networks, such as organizations and institutions, it can also be viewed as a site of structural constraints and contingencies. Focusing on work itself thus provides a meso-level analytical platform from which both "micro" and "macro" issues can be addressed.

Like many other medical and scientific practices, fetal surgery is performed by an elite group of specialists. Sociological perspectives on professions and specialties are thus useful in attempting to understanding the organizational contours of fetal surgery. Within such studies, medicine has often been assumed to be the profession

par excellence (Abbott 1988). Studies of professions take as a central problematic certain criteria which distinguish professional work from other types of work. For example, in an early account Greenwood (1957) described five characteristics of professions: a systematic body of theory, authority, community sanction, ethical codes, and professional culture. Roth (1974) highlighted several additional criteria, including autonomy, universalism, professional norms, and association with colleagues. Parsons (1975) believed that a health care system organized by an asymmetrical hierarchy between physicians and patients was functional for society; attempting to equalize this hierarchy would jeopardize the therapeutic benefits of the physician-patient relationship and the stock of medical knowledge that has been acquired over time. Finally, Freidson (1986:59), one of the most prolific theorists of the medical profession, argued that "a critical criterion lies in some degree of exposure to higher education and the formal knowledge it transmits."

What all of these perspectives share is an emphasis on the criteria separating professionals from other types of workers.[14] More recent perspectives have moved beyond this criteria-driven approach to articulate the historical, contextual nature of specialized knowledge and professional power.[15] A contextual theory provides an ecological model for understanding how professions, and professionals, emerge. Within such an "ecology of knowledge," as Rosenberg (1979:444) defines it, "the totality of any discipline or profession must be seen as a series of parallel intellectual activities being carried on in a variety of social contexts." A contextual theory does not take for granted traditional attributes assigned to professions, but rather acknowledges that criteria themselves are emergent and contingent. For example, while not rejecting the role of knowledge in professional formation, a contextual model

---

[14]In his Weberian analysis, Starr (1982) offers an understanding of professional power achieved through institutionalization of knowledge and the ambitions of the medical profession, and through professional authority granted to medicine by a willing public. His account describes many of the criteria traditionally considered essential to professions: knowledge, autonomy, community sanction, and professional culture.

[15]See, e.g., Abbott (1988); Burrage (1990); Larson (1990); Torstendahl (1990); Halpern (1992), and (Freidson 1994).

would examine the salience of knowledge as both historical and contingent, shaped by social, political, and economic factors. By emphasizing the emergent nature of professional criteria, a contextual theory would enable an assessment of professional *claims* to status and authority. Thus, a contextual theory of professions critically melds history with sociology.[16] It allows for investigation of the social structures within which professions emerge, while simultaneously acknowledging that social structures differ across time, location, and cultural context. It recognizes that knowledge is institutionalized, while paying attention to heterogeneous processes of institutionalization. These are important conceptual tools for undertaking an historical sociological investigation of fetal surgery.

Yet an important criticism might be lodged against professionalization theories. What is often missing in these analyses is a fuller critique of professionals' economic motives in pursuing certain lines of work. Here the work of political economists is relevant in situating professional work within the broader economic context of a capitalist health care system (Brown 1979; McKinlay 1984; Navarro 1986). In attempting to understand the emergence of fetal surgery, it is important to remember that surgeons are among the highest paid medical workers in the health care system. This is not to suggest that surgeons are simply self-interested economically and have no other motives. Rather, it is to include economic interests among the many possible reasons professionals pursue certain careers. As Light (1994:1197) argues, "subspecialization is grounded in scientific and technical research and in (let us be frank) the drive of the medical profession to extend and deepen its dominance. This has led to what can be called the 'professional capture' of health-care systems and their budgets." In other words, fetal surgery does not exist within some abstract version of medicine. It is part and parcel of a for-profit health care system in

---

[16]See Halpern (1988) for an insightful discussion of this issue in relation to the development of pediatrics.

which the altruistic goal of helping patients may exist alongside a range of other motivations.

Also relevant to understanding fetal surgery are interactionist perspectives on cleavages within professions, which may be along any number of "lines of work" (Hughes 1971), including work activities, sense of mission, methodologies and techniques, clients, colleagueship, or interests and associations. The domain of experimental fetal surgery is comprised of many such cleavages, or specialties, including pediatric surgery, obstetrics, sonography, nursing, genetics, social work, and others. Relationships among these different specialties have significant implications for the broader enterprise of fetal surgery. Identifying and understanding these "loose amalgamations of segments" (Bucher and Strauss 1961) in medicine is essential to mapping conflict, diversity, heterogeneity, and cooperation within practices such as fetal surgery. (This issue forms the core of Chapter 5.)

Bucher and Strauss (1961:258) view specialties as diverse, fluid, and historically contingent constellations of work activity. They argue that "segments are not fixed, perpetually defined parts of the body professional. They tend to be more or less continually undergoing change. They take form and develop, they are modified, and they disappear...In this process, boundaries become diffuse as generations overlap, and different loci of professional activity articulate somewhat different definitions of the work situation. Out of this fluidity new groupings may emerge." Analogous to actors engaged in political struggle, segments subscribe to ideologies in the form of professional identities and assume positions strategic to their goals. One goal may be formal specialization within the institutional framework of a profession. Bucher and Strauss (1961:259) argue that processes of specialization are shaped by institutional arrangements and that "a large part of the activity of segments is a power struggle for the possession of them or of some kind of place within them." This approach, which emphasizes heterogeneity, conflict, and change, is both theoretically

and substantively significant for understanding emergent specialties such as fetal surgery.[17]

The interactionist emphasis on fluidity, emergence, and contingent development of work is sustained in Bucher's (1988) analysis of health care occupations. Exploring the conditions under which occupational groups move through different phases draws attention to "what occupations do to forward and control their own development, and how they organize responses to structural conditions" (Bucher 1988:132). With respect to emergence, Bucher (1988:134) suggests that "the circumstances or social context from which an occupational group emerges is important because these circumstances set the initial structural conditions that the group has to face." Once occupational groups have emerged, they enter into a consolidation phase. As Bucher (1988:141) argues, "an occupation's position may never really achieve a *state* of consolidation. Instead, consolidating involves numerous activities in the service of the *strategic* problems of *continuing to secure institutional niches*." As Bucher (1988:142) emphasizes, consolidation is an ongoing process as occupational groups must respond to "changing internal and external conditions." Fetal surgery, struggling to secure an institutional niche, is currently located between the emergence and consolidation phases.

Moving away from a direct emphasis on professional work, sociological perspectives on medicalization are also useful in exploring fetal surgery. Medicalization is the process by which certain behaviors or conditions are assigned medical meaning or defined in terms of health and illness and therefore fall within the jurisdiction of the medical profession.[18] One such example with chilling consequences was the redefinition of homosexuality as a "disease" subject to medical treatment (Terry 1990). The medicalization framework thus highlights the degree of power

---

[17] See also Bucher (1962).

[18] See Riessman (1983) and Zola (1973, 1986).

physicians have in defining illness and deciding upon appropriate treatments. The labels of health and illness may depoliticize phenomena in that these labels locate both causes and treatments of problems in individuals, effectively defining them as non-social problems and hence not amenable to social policy solutions.

Because it involves the creation and transformation of definitions of health and illness, medicalization often results in whole new categories of patients and specialties. For example, neonatal technologies have made it possible to sustain premature and/or ill babies, called "neonates," as early as the second trimester of pregnancy. These practices raise a host of clinical, ethical, legal, and sociological questions about fetal viability, medical intervention, and moral accountability to these patients (Anspach 1993). Many other dimensions of human experiences and bodies have become medicalized in the twentieth century, most notably an array of women's health concerns.[19]

Of particular interest here is the medicalization of pregnancy and childbirth. Riessman (1983) argues that historically, obstetrics as a specialty group self-interestedly sought medical hegemony while women patients and activists advocated safer births. This dual process resulted in increased medical intervention in many facets of reproduction, including contraception, abortion, and pregnancy--all of which have increasingly become defined as pathological or disease states necessitating medical care.[20] Medicalization, then, provides both impetus and justification for social control of key aspects of women's lives by medical professionals. Defining reproduction as pathological enables physicians, who possess specialized knowledge and access to "therapeutic" technologies, to maintain a hegemonic position within health care vis-à-vis women consumers. It is little wonder that in such a context of

---

[19] See, e.g., Ruzek (1978); Lewin and Olesen (1985); Fisher (1988); Dan (1994); and Fee and Krieger (1994).

[20] See Stanworth (1987); Rothman (1989); and Petchesky (1990).

medicalization, many of my informants describe the uterus as the "final frontier" in medicine.

There are significant consequences of medicalizing aspects of pregnancy related to fetal health and well-being, many of which I explore in this dissertation. For example, obstetrics, traditionally focused on pregnant women as patients, has been transformed over the past few decades into a new hybrid clinical specialty called maternal-fetal medicine focused on *two* patients: mom and fetus (e.g., Creasy and Resnick 1994; Kaminetzky and Iffy 1979; Quilligan and Kretchmer 1980). Fetal surgery goes one step beyond this in its therapeutic focus on the fetal patient alone (Barron and Roberts 1995; Manning 1995); the pregnant woman becomes merely "the best heart-lung machine available" for maintaining the unborn patient. In addition, many fetal diseases are now the intensive focus of biomedical research initiatives aimed at identifying the root genetic and/or developmental causes of birth defects.[21]

Medicalizing fetuses thus means that high-cost, high-tech interventions are deployed for the (questionable) benefit of a few individual fetuses at the expense of a national concern with healthier fetuses and babies overall. An emphasis on innovative, cutting-edge treatment of structural birth defects draws our collective attention away from preventing such problems in the first place. Practices which ensure the healthy development of all fetuses, such as accessible and affordable prenatal care, a non-toxic environment, adequate nutrition, and the amelioration of poverty are displaced by headline-grabbing invasive treatments such as fetal surgery. In short, the medicalization of female bodies has now extended into a previously uncharted territory and, in the process, constructed a new object of the "clinical gaze" (Foucault 1973): the unborn patient.

---

[21]Within this reductionist framework, however, fetal pathologies are viewed as naturally occurring phenomena, rather than resulting from the hazards of human life in the late twentieth century. For example, the U.S. Centers for Disease Control has determined that the incidence of 29 types of birth defects is increasing and links this increase to environmental toxins rather than genetic defects (Edmonds 1990).

Social, Cultural, and Feminist Studies of Technoscience

Also useful for studying experimental fetal surgery are theoretical frameworks in social, cultural, and feminist studies of science and technology. This body of work is relevant for analyzing fetal surgery and related practices for several reasons. First, contemporary fetal research and treatment practices occur primarily within technoscientific and biomedical domains and thus constitute an appropriate analytical site for science studies. Fetal surgery is simultaneously shaped by both basic scientific research and clinical practices. Second, a hallmark of science studies approaches is the problematization of the distinction between the sociocultural and the technoscientific. This is crucial with respect to fetal practices, as fetuses are embedded, both materially and symbolically, in an array of often highly charged domains. Finally, because science studies is an interdisciplinary enterprise, it offers numerous opportunities for conceptual and practical linkages to other theoretical paradigms outside of science studies, such as medical sociology (Casper and Berg 1995).

Constructionist perspectives emerged in the 1970s in response to, and in dialogue with, earlier science studies approaches which failed to articulate the social nature of the contents of science and technology. The latter include functionalist, Marxist, philosophical, conceptual, and other realist paradigms, none of which challenged the long-standing hegemony of science as a distinctive, privileged *epistemology* ostensibly grounded in the pre-existing "natural" world. Functionalist perspectives in the sociology of science, for example, portrayed science as an institution with its own social structure and as distinct from the rest of society (Merton 1973; Zuckerman 1989), while Marxist and other political programs, although questioning the power of science in the social world, did not problematize its "cognitive/technical" core (Aronowitz 1988). Thus, in important ways these non-

constructionist approaches maintained analytical distinctions between the social and the technical, culture and nature, and practice and epistemology. Despite the diversity of contemporary constructionist perspectives, all share a rejection of the realism and philosophical apriorism so apparent in earlier approaches, as well as corresponding commitments to the social and cultural dimensions of science and technology. Science and technology, and increasingly "nature" itself, have thus come to be seen as sociocultural at their very core. This is significant in investigating and deconstructing such naturalized objects as the unborn patient in fetal surgery.

Early constructionist perspectives, defined under the rubric of the sociology of scientific knowledge (SSK), asserted that scientific knowledge must be understood as a social product. In contrast to the normative, armchair theorizing characteristic of the philosophy of science, the social nature of science was to be explored through *empirical* investigations, both historical and contemporary. As Clarke and Fujimura (1992:3) argue, these initial constructionist efforts were designed "to establish contingency itself" and paved the way for more intensive studies of scientific *practice*. Science studies scholars across disciplines began to pay attention to the concrete nature of scientific practice, or what scientists actually do, and its relationship to scientific knowledge. During the 1970s and 1980s, practice issues became a central feature of constructionist approaches and surfaced in studies of laboratory life (Latour and Woolgar 1979; Knorr-Cetina 1981), experimentation (Galison 1987; Gooding, Pinch et al. 1989), scientific inscriptions and representations (Hacking 1983; Lynch and Woolgar 1988) work practices (Star 1985; Clarke 1987; Fujimura 1987), and other areas. In short, the turn from science as knowledge, or epistemological questions, to science as practice (Pickering 1992) enabled constructionism to move beyond an exclusive focus on the social/technical core of science to the material, social, and technical conditions of its production, while recognizing that these are analytic rather than practical distinctions (Clarke and Fujimura 1992b).

The turn to practice offers science studies new tools for understanding the "nature" of science and technology, as well as for bridging the diverse fields and domains in which they are constructed, deployed, and used. With respect to investigating technoscientific work, in particular, there has been considerable interest in the concrete practices through which science and increasingly medicine are accomplished (Pickering 1992b; Casper and Berg 1995). Interactionist perspectives have focused on diverse aspects of science and medicine closely related to work, such as "doability" and "bandwagons" in cancer research (Fujimura 1987, 1988), the significance of research materials and tools to scientific work (Clarke 1987; Clarke and Fujimura 1992a), scientific controversies (Nelkin 1984; Clarke 1990), standardization, simplification, and uncertainty in scientific practices (Star 1983, 1985; Star and Griesemer 1989), and the day-to-day practices of scientists (Cambrosio and Keating 1988; Jordan and Lynch 1992). These perspectives situate work as a set of important social actions located at the intersection of social processes and orders, and many reflect a longstanding interactionist tradition in which *work as collective action* is taken as a central unit of analysis.[22] The social organization of technoscientific and medical work is seen both as a product of specific activities and as something which constrains and shapes broader arenas of collective action. This may also be framed as attention to local and wider conventions of practice.[23] These issues are explored more fully in Chapter 2 where I discuss the "nature" of work objects and their relation to other aspects of medical and technoscientific work.

Along with the turn to studies of scientific practices, there has been a corresponding interest in science as culture and in cultural aspects of science. This is useful in terms of situating fetal surgery within the cultural politics of reproduction. Pickering (1992:3) defines culture in this context as "the field of resources that

---

[22] See Bucher and Strauss (1961); Strauss, Schatzman et al. (1964); Hughes (1971); Strauss (1978); Strauss, Fagerhaugh et al. (1985); and Bucher (1988).

[23] See Clarke and Fujimura (1992b) for a discussion of this.

scientists draw upon in their work." Of course, this field extends beyond the confines of the laboratory or operating room to encompass a variety of resources in the "wider" culture. Scientific culture is thus construed broadly, raising the possibility of using the fluidity of culture and cultural resources as one way to analytically bridge the social/technical gap. Indeed, empirical studies of scientific practice would likely demonstrate that not only do scientists draw on an array of cultural resources in their everyday practices, but they also strategically channel their work through cultural fields in numerous ways for a variety of different purposes. An excellent example of research along these lines is Traweek's (1988) ethnographic study of high-energy physicists.

Not only are scholars in "traditional" science studies disciplines like history and sociology turning to studies of culture, but the field is increasingly infused with anthropological approaches (Downey, Dumit et al. 1992; Hess and Layne 1992; Rabinow 1992; Traweek 1992). Hess (1992), for example, outlines three ways in which an anthropological insistence on culture can reshape studies of medicine and science. First, these approaches direct science studies away from laboratory ethnography to a broader cultural critique of science, in which the social, cultural, and political meanings of science as discourse and ideology are examined. Second, the cultural critique of science is an interdisciplinary enterprise which integrates fieldwork-based ethnography of science with historical, comparative, and textual methods. Hess cites Martin's (1987) research on women's reproductive physiology as exemplifying this multiple strategy approach. Finally, Hess advocates reflexivity in ethnographic approaches to science and argues that "the question emerges of how one might inscribe the constructed nature of the anthropology of science in the social scientist's text" (1990:10). In short, anthropological approaches are viewed as "the vanguard of a new decolonizing discourse" within social and cultural studies of science and

technology. These frameworks are particularly useful in studying culturally laden and politically charged practices such as experimental fetal surgery.

Last, this dissertation also draws on feminist science studies. These approaches constitute an intervention, both epistemologically and politically, into what counts as social and cultural studies of science *and* into what counts as medical and scientific practices themselves. A major goal of feminist science studies is to (re)construct studies of medicine and science in ways that include heterogeneous actors and perspectives in order to reconfigure processes and accounts of knowledge production. Most feminist science studies approaches resemble constructionist critiques of science and technology, including questions about what comes to count as knowledge, who participates in knowledge production, the social and cultural fabric of science, and so on. Yet feminist critiques of science and technology differ from mainstream approaches in one very critical respect: *gender is central to the analysis.* As Hubbard (1990:17) puts it, "although women have not had a significant part in the making of science, science has had a significant part in the making of women." In terms of resituating pregnant women in the story I tell and reframing fetal surgery as a women's health issue, feminist science studies are invaluable.

Feminist science studies emerged in the 1970s as an intellectual component of the women's movement. From the beginning, these approaches have addressed both the epistemological grounds of science and the practical/political implications for women of science, medicine, and technology. Critiques have centered on eliminating sexist bias in the natural and social sciences, redefining objectivity and rationality, deconstructing dichotomies such as nature/culture, challenging the use of misogynistic metaphors in basic and clinical research, and resisting some of the ways in which science, medicine, and technology impact women's lives (Harding 1991). A central question for feminist science studies, as for feminist scholarship in general, relates to how gender, as an analytical category, fits into existing and emergent critical

perspectives. As Harding (1991:20) points out, "as feminists have discovered in every field, when one tries to add women and gender to conventional subject matters and conceptual schemes, it quickly becomes obvious that the two have been defined against each other in such a way that they cannot be combined." Consequently, the past two decades of work in feminist science studies may be read as attempts to explore and map the complex intersections of gender, feminism, science, and technology.

Like mainstream science studies, feminist science studies constitute a heterogeneous enterprise. There are a variety of approaches, substantive topics, disciplinary affinities, and political commitments inhabiting this diverse field. Topics in feminist science studies have included, for example, women in science and the impact of gender on scientific work (Rossiter 1982; Abir-Am and Outram 1987; Haraway 1989); feminist critiques of scientific epistemologies (Harding 1986; Longino 1990); historical accounts of the construction of sexual differences (Schiebinger 1989; Laqueur 1990); inquiries into contemporary constructions of sexual, racial, and other "essential" differences (Terry 1990; Martin 1991; Oudshoorn and Van Den Wijngaard 1991); futuristic accounts of the construction of sexual differences (Casper and Moore 1995), attempts to integrate analyses of gender with those of race and/or class (Gilman 1986; Stepan 1986; Harding 1989); medical, scientific, and technological constructions of, and inscriptions on, human (usually female) bodies (Terry 1988; Garber 1989; Balsamo 1992; Stabile 1992); and empirical studies of specific scientific practices and/or fields, such as primatology (Haraway 1989), genetics (Tobach and Rosoff 1978, 1980; Hubbard and Lowe 1979), and reproductive sciences and technologies (Clarke 1996; Hartouni 1991; Stanworth 1987). Despite their diversity, all of these perspectives reflect a shared understanding that knowledges and practices are gendered in multiple and consequential ways. My analysis builds on these contributions by recognizing the gendered content and context of experimental fetal

surgery in which the making of the unborn patient also involves the (re)making of pregnant women.

Unraveling the Politics of Reproduction

Because it concerns human fetuses, fetal surgery is, and has been since its inception three decades ago, closely linked to reproductive politics. I argue that this emergent specialty and the medical work which has shaped its development cannot be extricated from the cultural politics of reproduction.[24] For example, throughout his career William Liley forged linkages between politics and science, not only by developing fetal treatment technologies but also by founding New Zealand's major anti-abortion group, the Society for the Protection of the Unborn Child. Contemporary fetal surgeons have traveled the opposite path by attempting to carefully distinguish their work from abortion politics in the U.S. Either way, the politics of reproduction have provided a cultural and political frame of reference around which fetal surgery has been organized. Human fetuses are contested simultaneously at both "global" political and cultural levels of social life as well as at "local" levels of medical and scientific practices. Because of this dynamic, it is necessary to explore further what I mean by the politics of reproduction.

Feminist scholars have long been interested in reproduction as a critical and contested aspect of women's lives. Drawing on diverse theoretical perspectives and empirical frameworks, they have investigated abortion, pregnancy, childbirth, contraception, infertility, surrogacy, in vitro fertilization, menstruation, reproductive sciences, and reproductive technologies. Reproduction is seen a key site both of social control of women and of women's agency and self-determination, although these vary by race, ethnicity, and class. In the U.S., all reproductive processes, but

[24] See Clarke (1996) for an analysis of the emergence of American reproductive sciences within a social, historical context shaped by controversy over reproduction and sexuality.

particularly abortion, are contested at interpersonal, biomedical/scientific, and political/cultural levels of social life. Although there is a diversity of feminist positions, most feminists challenge technoscientific and biomedicalized constructions of reproduction by unraveling them to expose their social and cultural threads, as well as by articulating their implications for women.

Given their primary emphasis on women as actors and subjects, most feminist analyses of reproduction have not, until recently, directly addressed fetuses. In part this is because "the many paths through this politically-charged terrain are all lined with contradictions, creating a series of persistent conundrums for feminist analysis" (Morgan 1995:2). Within the past decade, however, feminist accounts of reproduction have begun to focus more explicitly on the fetus, largely in response to its emergence as a cultural icon in the guise of patient, person, and moral agent. Many feminists in the U.S. have come to realize that by not taking the fetus seriously in the current political context, they risk ceding this contested territory to anti-abortion and conservative forces. Feminist approaches attempt to deconstruct "the fetus" into multiple fetuses and (re)situate them within embodied frameworks in relation to the broader contexts of women's lives (Casper 1993). In other words, feminists problematize the fetal subject by refusing to take for granted its personhood, rights, interests, and/or moral value as constructed in medical, technoscientific, political, ethical, and legal domains.

These feminist scholars have begun to examine the social and cultural construction of fetuses.[25] They argue that fetuses are not pre-social entities already imbued with "natural" meanings and definitions. Rather, these authors suggest that fetuses are given meaning through a wide variety of social practices which are context-specific, culturally dependent, and widely divergent. A basic assumption of

---

[25] See, e.g., Rothman (1986); Petchesky (1987); Terry (1988); Morgan (n.d., 1989); Franklin (1991); Duden (1993); and Rapp (1993b, 1994).

feminist theorizing about fetuses is that these tiny yet significant entities form symbolic links between different groups of actors who struggle over the definitions and meanings ascribed to them. Not only are fetuses contested at the level of cultural politics, but they may also be highly contested within local domains as well. In this respect, analyses of reproduction have often focused on the medicalization of women's bodies and lives through surgical and other "therapeutic" interventions in women's reproductive health.

In general, feminist accounts of the fetus address three interrelated themes: the proliferation of cultural images and discourses of the fetus; sociocultural surveillance of pregnant women via technological surveillance of fetuses; and technoscientific constructions of fetal personhood and their implications. An overarching theme is how each of these patterns relates to the politics of reproduction. As discussed below, each of these themes imbricates the others, suggesting that fetuses are discursively and materially constructed out of intersecting sociocultural and technoscientific practices, with often profound implications for pregnant women. Fetal surgery may be seen as one such practice, as I discuss further in subsequent chapters.

Cultural Images and Discourses of the Fetus

One of the most consequential developments in the last two decades in terms of reproductive politics has been the emergence and proliferation of fetal images. Petchesky (1987:57), in her groundbreaking analysis, argues that the efforts of anti-abortion groups have shifted to "the terrain of mass culture and imagery...Not that the 'pro-life movement' has abandoned conventional political arenas; rather, its defeats have hardened its commitment to a more long-term ideological struggle over the symbolic meanings of fetuses, dead or alive." Within late capitalist culture, visual images of the fetus are perceived as reality rather than representation; simulacra

equals substance and threatens to "make fetal personhood a self-fulfilling prophecy" for anti-abortionists. The fetus has become a potent symbol in the late twentieth-century United States representing a range of competing interests, agendas, and desires.

Yet fetal images and constructions are also prolific in technoscientific domains as well. Reproductive technologies such as ultrasound are embedded in, and emerge from, the social relations of obstetrics and maternal-fetal medicine. Such technologies expand clinicians' control over reproduction by "carving out more and more space/time for obstetrical 'management' of pregnancy" (Petchesky 1987:68). This "panoptics of the womb" blurs the boundaries between fetus and baby, image and reality.

For clinicians, whose ways of seeing and knowing are shaped by the historical gender bias(es) of Western science, ultrasound images represent a multi-layered objectification of the fetus. At one level, fetal images constitute evidence pertaining to the fetus *qua* patient, which may facilitate diagnostic and/or therapeutic intervention. At another level, ultrasonographic images represent surveillance and potential social control of pregnant women. Petchesky suggests that these different levels of representation correspond to the ways in which ultrasound is embedded in the economic and patriarchal relations of obstetrics, as well as in Western scientific forms of knowing which privilege visualization. As she (1987:70) argues, "'evidence' shades into fantasy when the fetus is visualized...as though removed from the pregnant woman's body, as though suspended in space. This is a form of fetishization, [which] in turn, shades into surveillance when physicians, 'right-to-life' propagandists, legislatures, or courts impose ultrasound imaging on pregnant women in order 'to encourage bonding'" or to facilitate treatment.

Biomedical objectification of fetuses has serious implications for how pregnant women are perceived (or *not* perceived) within the social relations of obstetrics. Petchesky (1987:70) argues that fetal imaging techniques construct the pregnant

woman as a "'maternal environment,' the 'site' of the fetus, [and] a passive spectator in her own pregnancy." Yet at the same time, despite these negative constructions, diagnostic ultrasound often benefits women by making it possible to gauge due dates more accurately, to detect problems, and to anticipate delivery complications. Petchesky suggests that feminist critiques which emphasize "the war against the womb" are inadequate for understanding the complex tensions between imaging technologies and women's responses. As she points out, historical and sociological research has shown that women are not just passive victims of male reproductive technologies; they often participate in the emergence and proliferation of reproductive technologies for a variety of reasons. Feminist critiques of reproductive technology must thus account for women's desires and choices, even when they may seem contrary to women's own interests (see Chapter 6).

Where Petchesky (1987) is concerned with the proliferation of fetal images, Hartouni (1991:33) examines the emergence of reproductive discourses of the fetus and argues that "throughout this last decade, and particularly during its first half, public discourse and debate have seemed obsessively preoccupied with women and fetuses." She describes the significance of abortion debates to the emergence of this discourse, as well as the impact of Congressional hearings held in the early 1980s to determine fetal status. According to Hartouni (1991:35), "the fetus emerged from these hearings a 'person,' but one without constitutional protection and thus vulnerably situated in liberalism's mythic state of nature, where, even for the most clever postnatal entity, life is at best inconvenient and at worst [echoing Hobbes] solitary, poor, nasty, brutish, and short."

The legacy of these hearings, as well as of the abortion debates, is found in increasingly frequent appeals to scientific evidence and technological advances in determining fetal status. As Hartouni (1991:35) points out, fetal discourse and contestation over fetal status lends "concrete reality to the idea of the 'fetus as

person,'" and fetal personhood has significant implications for pregnant women, as we have seen. "Where gestation was itself once the most natural of processes, it has now become treacherous...Women are merely vessels, 'containers' that can be 'opened' in the name of fetal health even if such intervention places their own lives and health at stake" (Hartouni 1991:43). These developments Hartouni describes are especially apparent in the emergent practices of experimental fetal surgery and of keeping brain-dead women "alive" until their fetuses are viable, or what Murphy (1989) defines as postmortem maternal ventilation (PMV).

Hartouni discusses imaging technologies as a crucial constitutive element of fetal discourse and the stabilization of cultural meanings. For example, she deconstructs a television news program's statement that "with new technologies peering into the womb, women have been forced to peer into their hearts." Hartouni (1991:39) argues that this position poses a conflict between truth and desire: "on the one side is 'truth'--technology, objective observing, the womb as a thing in itself and the site of self-evident but only recently deciphered meanings, the uncovering of knowledge through scientific investigation; on the other side is 'desire'--women, self-reflection, the heart as the site of moral (maternal?) meanings, the recovery of knowledge through introspection." She also suggests (1991:41) that "'peering' technologies function as remedial aids. By exposing the interior life of the pregnant uterus, they enable women to reintegrate 'knowing' and 'doing' (through visual identification and bonding) or once again to 'read' all that is believed to be inscribed on their hearts and act accordingly."

Deconstructing discursive positions, Hartouni instead articulates the practices and relations of peering by raising questions of who, what, why, and so on. In other words, who is peering, what are they looking for, and why? For example, "someone (a physician?) is looking and looking for some 'thing' (the fetal patient?), for some purpose (diagnostic?), by 'consent' or with the cooperation of the woman in whose

body the womb is situated" (1991:40). That it is pregnant women's bodies which are peered into is significant, particularly when those peering have interests contrary to women's, including scientists and doctors who actually peer into women's wombs technologically, as well as other actors who literally or culturally peer, such as conservative Congressman Henry Hyde who sees "prenatal toddlers" inside the womb and "postnatal fetuses" outside of it.[26] In either case, peering excludes women except as bodies, objects of the medical, technoscientific, and/or political gaze.

Sociotechnical Surveillance of Pregnant Women and Their Fetuses

Some feminist researchers have investigated more explicitly the "peering" practices which give rise to diverse cultural fetal constructions. Terry (1988:14), for example, is fundamentally concerned with the implications for women of prenatal surveillance technologies such as amniocentesis, ultrasound, fetal monitoring, and intrauterine imaging techniques. She describes "a contemporary moment in which women of childbearing age and pregnant women in particular are subject to intensified scrutiny by both the state and civil society." Drawing on Foucault's analysis of *biopower*, Terry argues that bodily invasions of privacy via prenatal surveillance technologies are legitimized as necessary practices for the benefit of society. Where surveillance reveals unsuitable behavior, punishment is quick to follow in the form of forced contraception, forced cesarean sections, prosecution for drug use during pregnancy, and other emergent infractions. Women of color and poor women are especially subject to surveillance and punishment for deviant reproductive behavior.

As Terry argues, a key feature of late twentieth-century American politics is the appearance of formerly "private" subjects--specifically women, children, and animals--in the reconstituted "public" sphere. A consequence of the intersection of

---

[26]Hyde (R-Illinois), an outspoken conservative and anti-abortion legislator, was responsible for drafting the Hyde Amendment in 1977, which prohibits Federal funding of abortions for low-income women on Medicaid.

political liberalism with technological surveillance is the emergence of fetal rights. As described earlier, the discourse of fetal rights, like that of maternal-fetal conflict, constructs the fetus as an autonomous entity, independent of the pregnant woman in whose body it lives. Terry (1988:22) argues that "under the new regime of scientific panopticism, technologies that penetrate the body are deployed to heighten the imaginary division between the fetus and the pregnant woman." This divide has significant consequences for women's reproductive autonomy, particularly with respect to such practices as drug and HIV testing, genetic screening, and other forms of biomedical surveillance. Such practices create an *optical segmentation* of mother and fetus, as in the videos of fetal surgery where emphasis on the fetal patient is accomplished by opening the woman's body and partially removing its occupant.[27]

Specifically, Terry points to the politics of surrogacy and the inadequacy of a liberal rights framework for protecting women's "choice." She (1988:24) argues that the discourse of fetal rights presumes maternal-fetal conflict, in which "virtually every act of the pregnant woman has some effect on the fetus, since that intrauterine exile is completely dependent on [the] body of its keeper who surrounds it in the pre-panopticon dungeon." The alleged hostility of woman to fetus thus necessitates state and civil (i.e., biomedical) intervention on the fetus' behalf. Within a pluralist framework, the fetus becomes "an internal surveillance station for the occupying force inside the pregnant woman's body--the State. It provides the legitimating force behind 'lifestyle monitoring,' routine blood testing, genetic counseling, and incarceration of the incubating apparatus if she fails to fulfill her prenatal duties. The fetus is part of the design scheme of natal panopticism" (1988:28).

Stabile (1992) also analyzes sociotechnical practices through which cultural images of fetuses are constructed and deployed. Specifically, she examines the relationship between intrauterine imaging technologies (e.g., endoscopy, fetoscopy)

---

[27]I am grateful to Adele Clarke for suggesting this term.

and emergent ideological, legal, and biomedical distinctions between pregnant women and their fetuses. She argues that visual representations of anatomy, particularly of the pregnant female body, have "made possible the ideological transformation of the female body from a benevolent, maternal environment into an inhospitable waste land, at war with the 'innocent person' within" (1992:179). In Stabile's view, the construction of the humanist fetal subject is predicated on the erasure of women's material/maternal bodies and the reduction of women to passive reproductive machines.[28] As Stabile argues, "the maternal space has, in effect, disappeared and what has emerged in its place is an environment that the fetus alone occupies" (1992:180).

Stabile draws on historical and contemporary photographic representations of the fetus in a popular magazine at two different periods, 1965 and 1990, to illustrate the dichotomy between pregnant women and their fetuses as historically unprecedented. She argues that comparisons of these images highlights ideological shifts around the categories of "woman" and "embryo/fetus," and shows how the different texts invoke visual technologies for specific political reasons.

In 1965, for example, when images of a "living 18-week-old fetus" first appeared in the pages of *Life*, abortion was illegal and pregnant women were not constructed as threats to their fetuses. As Stabile points out, "in 1965, the mother can be shot through, but she does not need to be erased: traces of her presence remain, both discursively and through the inclusion of the placenta in the photographs" (1992:186). In the 1990 *Life* photographs, however, there are no images of either the amniotic sac or the placenta, and the accompanying text carefully distinguishes the embryo/fetus from the female body. Stabile remarks that these images appeared just as abortion rights, existent for almost two decades, were being increasingly

---

[28]This, of course, raises the question of where women's agency and subjectivity are located in Stabile's account.

challenged by conservative forces on multiple levels. Within this context, pregnant women were (and are) construed as threats to their fetuses, not only through abortion but as a result of their supposedly unhealthy everyday practices. Thus, in 1990 the mother is both "shot through" *and* erased by visual imaging technologies.

Ironically, both the 1965 and 1990 images emphasize the "never before seen" nature of the photographs. Stabile argues that these repeated claims to originality seem designed "to secure authority in the debates about the ontological status of the fetus" (1992:188). Such claims are central to abortion conflicts, in which the concept of *viability* is deemed a critical determinant. Yet fetal viability shifts along with emergent imaging and other reproductive technologies, which threaten to render the term obsolete. As Stabile points out, "today, the photographs imply, we can now photograph 'early life,' but tomorrow we may well be able to sustain it through technology" (1992:190).

Like Petchesky (1987), Stabile reminds us that the consequences of these visual images of fetuses are significant. Such technological representations are not limited to the pages of *Life*, but are rather deployed in many cultural domains for political and other purposes. In the fall of 1990, for example, anti-abortion protesters visually assaulted women entering abortion clinics in Cranston, Rhode Island, with copies of the 1990 *Life* images (Stabile 1992). Larger-than-life fetal images generated in medical and technoscientific domains are also routinely pasted onto signs for use at anti-abortion demonstrations. A feminist inquiry must be: Where else and to whom are these images displayed and deployed?

The erasure of the female body via imaging technologies also functions to erase pregnant women's contributions to the labor of reproduction. With the disappearance of the material/maternal body, the only actor left is the fetus, and perhaps its spokesmen [sic] in the New Right. As Stabile argues, "put bluntly, at this particular historical moment, only 'women' can carry out the work that is pregnancy.

Furthermore, as long as this specific laborer remains invisible, the discourse of fetal autonomy is going to be difficult to overcome" (1992:198). Stabile's account is thus an invitation to feminists to begin theorizing pregnancy as a biosocial process distinct from mothering. Until feminists engage these issues, she argues, the difficult task of disarticulating the pregnant body from the maternal body will remain unresolved. Stabile's invitation is appealing, as fetal surgery is an exceptionally potent site for theorizing pregnant bodies and pregnancy at a number of levels.

Technoscientific Constructions of Fetal Personhood

One way in which feminists have begun to (re)conceptualize pregnancy is by analyzing fetal personhood and articulating its implications for women. Franklin (1991:190) presents an acute analysis of the emergence of fetal personhood as a cultural category, linking technoscientific constructions of the fetus with their deployment in cultural domains. She argues that this "can be seen as a development which is consistent with the increasing medicalization of the abortion debate, and the reliance upon abstract scientific criteria, such as 'viability,' to define the abortion question." Franklin (1991:191) argues that the contemporary abortion debate is "now more than ever an explicit struggle over the definition of a key set of 'natural facts,' the so-called 'facts of life.'" She suggests that biological accounts of fetal ontology are symbolically powerful as key cultural resources in the construction of personhood. Technoscientific practices construct the pregnant woman and her fetus as distinct individuals with competing interests.

Where fetuses are seen as autonomous individuals, pregnant women are "fragmented into being and non-being, at once the mother and the maternal physiology that constitutes the fetal environment" (1991:194). I would call this the move from optical segmentation to physical segmentation. Not only is the fetus separated from the pregnant woman via technoscientific constructions and interventions such as fetal

surgery but the social is also distinguished from the biological. Although biological facts are culturally constructed, the social category of fetal personhood is elaborated out of "natural facts." Thus, Franklin (1991:196) argues, "the ontology of fetal being is [constructed as] entirely asocial," a "fact" that resonates in abortion debates where the validity of fetal ontology is a central element.

Another aspect of this story is teleological fetal constructions as key elements in the cultural elaboration of fetal personhood. Teleology here refers to the progressive, continuous physiological development of the human organism. In this framing, "life" begins at conception, the fetus is viewed as a potential adult human being, and fetal *potentiality* is equated with fetal *individuality*. Franklin (1991:200) argues that teleological constructions render invisible not only pregnant women, but society and kinship as well. "The potential for biological life completely obscures all other dimensions of human life, and is seen as a justification in itself for the right to exist...Biology thus not only obscures social categories, but it becomes the basis for their cultural production." She suggests that "it is an awesome measure of the power of medico-scientific discourse that it can accomplish this simultaneous erasure and replacement of something so basic to human social life as reproduction through the power of its exclusive claim to represent the truth of 'natural facts.'" This is a deeply biologically determinist argument in which culture and society are deleted in discourse.

Rothman (1989) also is interested in the implications of fetal personhood, which she defines as "fetal power." She situates her analysis within a discussion of the social relations of pregnancy and argues that assumptions of maternal-fetal conflict based on constructions of fetal personhood are deeply embedded in contemporary obstetrical practices. Within these frameworks, the view of pregnancy as a social relationship between a woman and her fetus is disregarded in favor of a biomedical approach that views the fetus as a distinct patient with needs and interests of its own, which often require protection by a fetal advocate who is *not* the pregnant woman.

Rothman suggests that this perspective assumes its most pernicious form in coerced medical treatment of pregnant women for the benefit of their fetuses. She (1989:163) points to fundamental problems with obstetricians invoking the state to control a pregnant woman's behavior in the interest of her fetus: first, "obstetrics has too long a history of errors in management for us to be certain that obstetricians always know the best interests of the fetus...[Second,] the costs to the civil liberties of pregnant women are too high. We are in danger of creating of pregnant women a second class of citizen, without basic legal rights of bodily integrity and self-determination."

In place of the maternal-fetal conflict paradigm and state control in reproduction, Rothman (1989:165) proposes a feminist view of pregnancy as a biosocial relationship in which "women and their fetuses are bound together, and enmeshed in a social world." This approach would recognize that women make decisions about their health, including reproduction, for a variety of reasons. As Rothman (1989:168) points out, "being pregnant complicates a woman's medical decision making, but so do all our social and moral obligations...the presence of a fetus in her body complicates a woman's decisions--but it makes them no less *her* decisions."[29] Thus, in Rothman's account fetal personhood is destabilized by situating the fetus within a social, embodied framework in which women's needs and experiences are paramount.

Like Franklin (1991) and Rothman (1989), Rowland (1992) problematizes fetal personhood by placing pregnant women at the center of her analysis. She argues that fetal personhood represents a threat to women's reproductive autonomy by constructing pregnant women as "dissolving capsules" whose rights and interests are subsumed within those of the fetus. She (1992:122) also suggests that "it is no accident of history that the emphasis on the fetus as a patient with 'rights' comes at

---

[29]Rothman (1986) has explored in greater detail the complicated nature of reproductive decisionmaking via an analysis of prenatal screening technologies, illustrating the agonizing choices that pregnant women are often compelled to make. See also Rothenberg and Thomson (1994) and Ginsburg and Rapp (1995).

the time when women are demanding more control over pregnancy and birth...The technologies developed to monitor, save, 'improve' or discard the fetus endanger this control...By giving the fetus rights, medicine ends up by giving it greater rights than a woman."

Rowland traces the emergence of fetal personhood through a range of technoscientific and cultural practices, including coerced cesarean sections, hazardous workplace legislation, prenatal screening technologies, fetal treatment practices, and practices which use fetal material, such as fetal tissue research and transplantation. She argues, for example, that technologies and practices which make the fetus accessible for visualization and/or manipulation construct the fetus as a patient, while simultaneously depersonalizing the pregnant woman. In her view, fetal treatments such as surgery render women invisible as subjects and reduce them to bodies which must be opened in order to reach the fetus. Rowland points out that while fetal treatments are considered experimental, what remains unacknowledged is that women's bodies are experimented on as well. Scientific discourse around fetal tissue and organ procurement also tends to mask the origins of fetal material in women's bodies. Rowland refers to these practices as "gross exploitation" of women and raises the specter of fetal farming, black markets in fetal parts, and "forced bodily intrusions" on pregnant women.

Although Rowland places women at the center of her analysis, she does not take women's subjectivity seriously. In her radical feminist account, women are exploited, victimized, and negatively constructed by science and medicine. Her discussion of fetal surgery, for example, portrays women as passive, unwilling victims of misogynistic surgeons. Unlike other feminist perspectives discussed here, Rowland's analysis leaves little room for female agency or differences among women. Hers is not a nuanced account of the complex intersections of pregnant women, doctors, technologies, fetuses, and other elements in this domain; it is rather a

sweeping indictment of *all* fetal practices along with all new reproductive technologies, with little concern for the possible ways in which women might be active participants in constructions of fetal personhood and seekers of intervention. Ironically, while Rowland's account problematizes the fetal subject, it essentializes women and renders female subjectivity inconsequential (see Chapter 6).

The array of feminist social and cultural perspectives on the fetus discussed here both undergird and inspire my research. Despite their diversity, taken as a whole these accounts problematize the fetal subject in its multiple incarnations. This involves more than just (re)situating the fetus within an embodied framework in relation to women's lives and social relations. It also requires an understanding of women's desires, interests, and needs, as well as the articulation of how female subjectivity is implicated in the emergence and maintenance of reproductive practices and technologies. Feminist approaches to reproduction must acknowledge that women are not only embodied, but that they are also social and cultural actors. This approach has important implications for how the fetus is conceptualized in feminist research on reproduction, including fetal research and treatment practices such as fetal surgery.

Caveats and Overview of the Dissertation

This introduction is a map of sorts to lead readers on their journey through the topography of my dissertation. I have thus far located fetal surgery as a new biomedical specialty and described the contours of this practice. Theoretical perspectives germane to investigations of medical work and the politics of reproduction have also been discussed. In this section, I provide an overview of the rest of the dissertation, beginning with a brief discussion of what this project does not do. The overview is designed not only to orient readers to the project as a whole, but also to allow my audience(s) to select those chapters of most interest to them.

However, because the imbricating themes of medical work and the politics of reproduction undercut all of the chapters, it is my hope that audiences will find the entire dissertation worth traversing.

In brief, this dissertation will *not* do several things, although it may well point to some areas that need to be researched. First, it is not an epidemiological analysis of outcomes, selection factors, or long term follow-up of fetal or maternal patients.[30] Second, this dissertation does not analyze the politics and cultural significance of birth defects, although certainly these issues undergird social desires to screen for and "fix" ailing and deformed fetuses.[31] Third, I am also not presenting a historical analysis of teratology, the study of "monsters," although this is a fascinating subject and may well illuminate contemporary concerns about fetal health.[32] Fourth, I have not conducted a study of surgery per se, but rather of a particular kind of surgery on a particular biomedical object/subject.[33] It is also not a history of the entire field of fetal treatment, which is sorely needed, nor a comprehensive overview of how fetuses are conceptualized within science and medicine, although I do address some aspects of this.

Last, this dissertation is not a complete story. Some voices are missing, even though they are part of the broader domain of fetal surgery. For example, although I have discussed abortion with many of my informants, I have not fully researched abortion activists' positions on fetal surgery. Also, I have not talked to all of the pregnant women who have undergone or are considering fetal surgery. A fuller, richer

---

[30]To my knowledge, there have been no studies of fetal surgery from an epidemiological or public health perspective. See Harrison (1991b) for a discussion of *clinical* selection factors and Longaker et al. (1991) for a review of outcomes of fetal surgery for congenital diaphragmatic hernia. There have also been no published long-term follow-up studies of fetal surgery patients, either fetuses or pregnant women.

[31]Most social and cultural analyses of birth defects focus on genetic screening; see Rothman (1991), Lippman (1992), Rothenberg and Thomson (1994), Rapp (1993d; 1993b; 1994), and Ginsburg and Rapp (1995). Ethicists have also taken up issues related to birth defects (Overall 1990).

[32]Teratology has been addressed largely within historical studies of embryology (Gilbert 1991), although to my knowledge there has not been a comprehensive historical, sociological investigation of this macabre specialty within biology.

[33]For a fuller discussion of the history of surgery in the U.S., see Brieger (1980). For a more contemporary account of surgery as a cutting-edge medical practice, see Hirschauer (1991).

account would require access to all of the actors in the domain of fetal surgery, especially the pregnant women who have sought and/or experienced it. Further, because fetal surgery has been virtually unstudied by social scientists, this is also a pioneering study in many ways. Hopefully my account will spur others to investigate fetal surgery from an array of perspectives and help to fill in some of the gaps in our knowledge of this nascent practice.

Centering this dissertation are the twin threads of medical work and the politics of reproduction. I use a variety of different theoretical tools to analyze fetal surgery and the social dynamics which have shaped it: sociological approaches to work; social and cultural studies of science, technology, and medicine; feminist studies of reproduction; medical historiography; and cultural studies. Further, I draw on a diverse range of data sources and utilize different qualitative methodologies to analyze them. A fuller description of my data sources and methods is presented in Appendix A.[34] More specifically, my dissertation is organized as follows:

Chapter 2, "Theorizing Work Objects in Medicine and Science: A Comparative Analysis of Fetal Practices and Politics." In this section I explore in greater depth my original concept of *work objects*. I begin by elaborating interactionist studies of work to include theoretical questions about the material objects of that work. To rupture the taken-for-granted, I identify pregnant women and their fetuses in these domains as *technofetuses* and *technomoms*, pointing to the reconstruction of fetal and maternal subjectivities through technological intervention. Through a comparison of different fetal practices in science and medicine, notably fetal surgery and fetal tissue research, I examine how fetal work objects are constructed differently

---

[34]In Appendix A, "Methodological Strategies and Quandaries," I review my methods, including data sources and analytical strategies. I also discuss some methodological issues involved in "studying up" in research on doctors, scientists, and other elites, including informants' power to impede access to research. In addition, I raise some feminist epistemological questions about "taking sides" (Becker 1977) in sociological research, discussing such research in terms of accountability and responsibility to informants/subjects. I attempt to carve a space for critiquing certain social practices while respecting the perspectives and lived experiences of women who actively engage in those practices.

across different practices. In particular, I discuss the contested nature of fetal and maternal work objects and their location within contemporary reproductive politics.

Chapter 3, "Breaching the Womb: Historical Emergence of the Fetal Surgical Patient." Drawing on historical research I conducted in New Zealand, Puerto Rico, and key U.S. locations, this chapter explores early fetal surgery efforts in both animals and humans in the 1960s. I follow the work of three major figures, the late Dr. William Liley, Dr. Karliss Adamsons, and Dr. Vincent Freda, as well as the work of their many colleagues and collaborators. Liley, generally identified as the "father of fetal surgery," pioneered fetal transfusion therapy in 1963; his work provided an important foundation for subsequent fetal therapy. In addition to his preeminence as a scientist and medical figure in New Zealand and internationally, Liley also founded the Society for the Protection of the Unborn Child there, illustrating the close interweaving of his "personal" and "professional" lives. San Juan-based Adamsons worked with Liley and Freda at Columbia University in New York in the 1960s before returning to Puerto Rico. Although much of Adamsons' and Freda's work was done on non-human primates, they attempted open fetal surgery in humans as early as 1965, with limited success. Their efforts, like Liley's, served as a foundation upon which later work was based. As with contemporary fetal surgery practices, historical efforts were also undergirded by the cultural politics of reproduction as shaped by specific national contexts. This chapter thus situates contemporary practices within the historical context of earlier efforts.

Chapter 4, "A Hybrid Clinical Practice: Intersections of Medicine, Science, and Technology in Fetal Surgery." This chapter explores issues stemming from fetal surgery as an emergent but not yet consolidated specialty, located somewhere along the continuum between "experimental" and "routine" medical procedures. Rather than viewing medicine, science, and technology as distinct entities, this chapter discusses them as intertwined parts of what I call hybrid clinical

practices. Fetal surgery is shaped not only by the clinical work of medical practitioners, but also by the intersections of basic scientific research and technological innovations with medical work. Building on both historical and contemporary data, this chapter explores fetal physiology, diagnostic technologies, animal experimentation, and fetal wound healing research as these practices have shaped fetal surgery. In different yet interrelated ways, each of these practices have enhanced access to the fetus, thereby participating in the construction of the unborn patient.

Chapter 5, "Working On and Around Human Fetuses: The Heterogeneous Domain of Contemporary Fetal Surgery." Based on data collected in the Fetal Treatment Unit (FTU) at Hilltop Hospital, this chapter examines the institutional framework of contemporary fetal surgery. I focus specifically on the work done by many of the relevant medical practitioners in this domain. Using the concept of fetal and maternal work objects, the specialty of fetal surgery is presented as a heterogeneous and contested domain in which actors must negotiate social order in the face of conflicting perspectives, agendas, and work practices. Key questions in this chapter are: Who or what are primary work objects? Who decides what are primary work objects? Under what conditions? With what consequences? How do institutional hierarchies shape this process? These questions are addressed through an analysis of several areas where differences matter in fetal surgery: definitions of work objects; factors in patient selection; and definitions of a fetal disease and its treatment.

Chapter 6, "'Heroic Moms' on the Reproductive Frontier: Maternal Practices in Fetal Surgery." This chapter examines pregnant women's experiences in fetal surgery through an analysis of a range of "maternal practices" (Scheper-Hughes 1992). I am interested here in the varied work that pregnant women do in fetal surgery as well as in the work done on pregnant women by medical practitioners.

I define pregnant women as *engaged* participants, focusing on their choices and politics in fetal surgery, the organizational and body work they do, and women's assumptions of health risks as examples of their engagement. I also address tensions in fetal surgery stemming from the materiality of performing an operation in which the fetal patient is located inside a woman's body. These include maternal management strategies, the informed consent process, and the significance of lay versus professional control in clinical decisionmaking. I show that pregnant women in fetal surgery are both working subjects and work objects; engaged and implicated actors; part of social maternal/fetal relationships and enmeshed in discourses of maternal/fetal conflict. Drawing on these tensions, I reframe fetal surgery as a women's health issue to allow for a more nuanced analysis of the diversity of women's reproductive experiences and choices and of the broader discourse of "choice" itself.

Chapter 7, "Beyond the Operating Room: Conclusions and Implications." This chapter will summarize my key arguments, discuss implications of my research, and suggest some possible avenues for further research.

Epilogue, "Whither Fetal Surgery?" Here I present a brief preview of the future of fetal surgery as envisioned by some of my informants.

****

In describing the historical emergence of the fetal patient, Harrison (1991:3) states, "It was not until the last half of this century that the prying eye of the ultrasonographer rendered the once opaque womb transparent, letting the light of scientific observation fall on the shy and secretive fetus" and revealing that it "does not at all resemble the passive parasite that we had imagined." My dissertation is about letting another, more critical kind of light fall on fetuses and on the medical practices surrounding and sustaining them. I draw on the "sociological imagination" (Mills 1959) to construct new ways of thinking about the fetus as an icon and about

Chapter 2

THEORIZING WORK OBJECTS IN MEDICINE AND SCIENCE: A COMPARATIVE ANALYSIS OF FETAL PRACTICES AND POLITICS

"Symbolization constitutes objects not constituted before, objects which would not exist except for the context of social relationships wherein symbolization occurs...Objects are in a genuine sense constituted within the social process of experience..."
(Mead 1934:67)

In Chapter 1, I introduced experimental fetal surgery as an emergent specialty, focusing both on theoretical issues and on descriptive information. In order to fully understand this new field, it must be situated within the context of other fetal research and treatment practices, both historically and at present (Casper 1993).[1] It is only in recent decades that the human fetus has become simultaneously both a medical patient *and* a scientific work object (Bookstein 1990; Harrison 1991), and a contested one at that. Fetal physiological and embryological research in the early- to mid-twentieth century established important groundwork for contemporary developments in fetal research and treatment. Experimental fetal surgery is itself part of a larger world of maternal-fetal medicine that includes non-invasive treatments such as bed rest and drugs and invasive treatments such as transfusions and endoscopic manipulations (Creasy and Resnick 1994). In the period from World War II to the present, in addition to experimental fetal surgery, "advances" include attempts to use fetal tissue as a therapeutic technology in the treatment of diseases and fetus-to-fetus transplantation of tissue and cells. Each of these domains of biomedical and technoscientific practice on or using fetuses represents a constellation of particular fetal constructions which are both compelling and consequential.[2]

---

[1]Historical aspects of fetal treatment practices will be taken up in Chapters 3 and 4.

[2]My use of the term *construction* derives from social constructionist perspectives in sociology and social studies of science (Berger and Luckmann 1966; Latour and Woolgar 1979; Knorr-Cetina 1981; Pickering

Yet, because human fetuses are so meaningful in many walks of life, fetal surgery must also be situated within other practices and contexts such as cultural politics and social policy. The heterogeneity of fetal constructions across multiple domains potently illustrates the fetus as a contested entity at/as the intersection of diverse work activities and sites. Such contestation seems fairly obvious with respect to sociocultural and political framings of fetuses; for example, abortion controversies in the U.S. have situated the fetus at the center of vitriolic and now often violent confrontations. However, fetal contestations are less evident in scientific and biomedical domains where the fetus is often viewed as a distinctly *natural* entity, its cultural meanings obscured in the arcane language of scientific facts (Grobstein 1988; Morowitz and Trefil 1992). Indeed, science and medicine are often called upon as "objective" mediators of *social* conflicts involving the fetus, as in the 1973 Supreme Court decision legalizing abortion. In contrast, my account treats *all* domains in which the fetus is situated, including medical and technoscientific work practices, as potential or actual sites of contestation. Any comprehensive understanding of the fetus in the contemporary United States must address the dynamic multiplicity of fetal constructions and their diverse contested ecologies.

As a way of situating experimental fetal surgery per se vis-à-vis other contemporary fetal practices, I locate the fetus as a *work object* in multiple domains and maps its peregrinations across different terrain. For example, fetal and maternal work objects are located within both medical and technoscience worlds *and* within the domain of contemporary reproductive politics. I theoretically define the fetal work object as the analytic center of my research in order to examine who cares, in a pragmatist sense, about human fetuses.[3] By whom and in which worlds are meanings

---

1992b). I employ the term in the broadest sense possible to refer not only to cultural, semiotic, and discursive constructions of fetuses, but also to material, physical, and technical constructions.

[3]This approach is derived from social worlds theory (Strauss 1991; Clarke 1991) in which the object of interest is placed at the analytic center. Analysis then proceeds along the lines of "Who cares," in a pragmatist sense, about that object. Everyone who cares, and who is implicated, is then included in the analytical domain.

attributed to human fetuses? How do these meanings connect to fetal representations in other domains? In attempting to grasp how medicine, technoscience, and culture are linked, it is useful to focus on the material and symbolic objects which constitute the traffic between these overlapping worlds. This approach addresses core sociological questions about social organization, collective action, and meaning, while simultaneously resonating with anthropological and cultural studies perspectives on how subjects, knowledges, and technologies are produced and maintained within specific cultural contexts (Rouse 1993; Downey, Dumit et al. 1995).

In this chapter, the concept of work object is defined in theoretical terms and linked to both interactionist and technoscience studies frameworks. I point to some key elements of this concept and discuss its relation to others, such as tools (Clarke and Fujimura 1992a) and research materials (Clarke 1987, 1996a, 1996b). This concept enables a comprehensive understanding both of the medical and technoscientific practices involved in working on fetuses and of how these practices relate to the broader cultural milieu within which they are situated. Further, as a way of emphasizing the highly technical nature of work on fetuses and pregnant women in fetal surgery, and the extraordinary investments made in them, I introduce and elaborate my concepts *technofetus* and *technomom*. I next comparatively examine experimental fetal surgery and fetal tissue research as exemplars of heterogeneous fetal practices through which fetal and maternal work objects are varyingly contested and constructed. Last I raise key theoretical issues implied by conceptualizing and applying work objects in the ways I have described which frame the dissertation analysis.

Defining and Conceptualizing Work Objects

An important interactionist contribution to understanding work objects is Mead's (1934) notion of *social objects*. In this framing, people are seen as living and

working within contexts of meaningful objects, which are conceptualized as human constructs rather than as "self-existing entities with intrinsic natures. Their nature is dependent on the orientation and action of people toward them."[4] In this view, an object, including its classification as either human or non-human, is defined according to the meanings it has for the actor(s) for whom it is an object. These meanings derive from the ways in which a person acts toward an object, rather than from any *inherent* nature or quality of objects (emphasis added). Objects are conceptualized as social products in that "they are formed and transformed by the defining process that takes place in social interaction."[5] The nature and quality of objects are themselves seen as social constructs in this framing. As Blumer points out, "to identify and understand the life of a group it is necessary to identify its world of objects; this identification has to be in terms of the meanings objects have for the members of the group."[6]

An important challenge to Mead's "humanist" view is raised by perspectives in science studies which argue for the significance of non-human actors, or what in actor-network theory (ANT) are called *actants* (see, e.g., Callon 1985; Latour 1988). Specifically, ANT asserts the importance of actants as *participants* in sociotechnical domains. Both humans and non-humans are seen as interrelated elements or nodes in heterogeneous networks of practice. Theoretically, ANT strives for analytic symmetry and accords primacy neither to the natural/technical nor to the social/cultural; indeed, it attempts to do away with these divisions altogether. Hence, meaning and its attribution are not significant analytical issues for actor-network theorists. It is participation itself, rather than the meanings ascribed to participation, that matters in ANT accounts. For example, in Berg's (1995) study of decision support techniques in

---

[4]Blumer (1969:68).
[5]Blumer (1968:69).
[6]Ibid.

medical practices, the tools are given equal analytical weight to the human actors.[7] In short, actor network theorists argue that non-human entities, just as much as humans, are important constituents of technoscientific practices.

Yet ANT is insufficient for fully grasping how, exactly, humans and non-humans interact in networks. By not focusing on meanings, ANT fails to capture adequately how human actors both represent and interpret the non-human animals and objects that surround them. If Mead stands accused of being too human-centered, then ANT may be accused of being too techno-centric. In treating humans and non-humans symmetrically, ANT seems to forget that networks as we know and experience them, and any analysis of these networks, exist within human cultures. This is not to assert humanism in a privileged way, with "us" humans lording over the other creatures in the jungle and the technologies in the lab. Rather, it is to recognize that all knowledge is situated knowledge (Haraway 1991); there is no other way in which we humans can understand the world than *as humans*. In demanding symmetry between the social and the natural, actor network theorists claim to be merely following all the different entities. Yet their claims to symmetry mask *their own* attribution of meanings to all the entities in their accounts. In dismissing the significance of human meaning, including their own, actor network theorists end up portraying actants in a realist way, as if the humans were one thing, and the non-humans another, both in "nature" and extant within networks.[8] Social action, both of the object and the analyst, is obscured.

Perhaps there is a middle-ground between Mead's humanism and ANT's anti-humanism, one more akin to co-constructionism (Clarke and Fujimura 1992b; Fujimura

---

[7]As Berg (1995:85) argues, "one of the central tenets of [science and technology] studies is that the development of a technology cannot be properly understood from perspectives which treat Nature and Society as separate realms, and which confine explanatory power to either one of them."

[8]Collins and Yearley (1992:372) frame this as such: "[W]hen the scientist says 'scallops' we see only scientists saying scallops. We never see scallops scalloping, nor do we see scallops controlling what scientists say about them." Likewise, we never "see" humans and non-human interacting in networks, we merely read about them in ANT accounts.

1992; Pickering 1992a; Casper 1994). Building on both Mead's definition of social objects and science studies perspectives emphasizing non-human actants, I have developed the concept of *work objects* to more fully grasp the intricacies and concrete dimensions of material aspects of work and its place in social organization. I define work objects as the material entities (human, non-human, technical, or hybrid) around which actors construct meanings and organize their work practices. In sociological research on work, little attention has been paid to the objects of work.[9] The analytical significance of focusing on work objects is in examining how the "nature" of the object, or its material and symbolic characteristics and properties, shapes work practices and how the object itself is simultaneously and mutually shaped by the work and its social contexts. In this framing, analytical emphasis remains focused on human action and meaning (Strauss 1993), yet incorporates an understanding of how material, physical work objects may constrain, enable, or otherwise influence these processes.

Specifically, although epistemological knowledge of what the object "really" is rests on human attribution of meaning (Berger and Luckmann 1966), objects may have particular qualities, characteristics, or properties which in turn shape constructions of reality in important ways. Objects may be recalcitrant, stubborn, and constraining; they may not always do what human actors expect, hope, or plan for. They may provide wondrous new unanticipated opportunities. They may serve as key resources or tools for getting things done. In other words, the nature or quality of the object *does* matter in sociological investigations of work, as ANT asserts. Yet, as Mead recognized, this materiality is made meaningful through our interpretation of it. This represents a simultaneously materialist and constructionist framework. That is, properties and characteristics are social constructions as well as things in themselves. Focusing on work objects injects a dynamic, processual awareness of

---

[9]In a roundabout way, medical sociology has moved in this direction by focusing intently on patients as work objects, although this has not been articulated theoretically or explicitly.

work practices, in that the people and things worked on are seen as significant factors in the overall shape and trajectory of the work.

Analytically, the relationship between work objects and how work practices are organized is a local empirical question. For example, there may be one or multiple work objects within any domain of practice. Several practitioners may share a work object, while one practitioner may have many. Where there are multiple work objects, these may be organized or assigned meaning by actors hierarchically, with primary work objects, secondary work objects, and so on. Other important dimensions include various and contested definitions of work objects, who claims work objects and consequently makes decisions about them, how work practices are organized around work objects, how both work objects and work practices may change as objects move through and across different domains, transformations of the work object across time and space, and constraints on practice resulting from their materiality. For example, work objects may enable or constrain certain "lines of work" (Hughes 1971) within scientific practice, thus shaping the types of research questions scientists pursue and the means by which they address them. Haraway's (1989) account of primatology is an excellent example of this.

Work objects are also usefully related to other concepts within research on medicine and technoscience. For example, Clarke and Fujimura (1992b:3) define *tools* as the materials, techniques, instruments, models, and so on that enable scientific work. The embeddedness of the "right tools for the job" within concrete practices forms the "nitty-gritty of scientific work...Doing science involves multiple different tools, processes, and participants and their articulation across time and space." However, where tools enable work, objects provide a concrete focus for the work. Yet the distinction between work objects, as I define them, and tools is both dynamic and fluid. For example, one scientist's tool might be another scientist's work object, as when fetal surgeons view sonographic images as tools for clinical evaluation while

radiologists view such images as primary work objects. Of course, work objects can also be tools; for example, fetuses are both tools and objects through which fetal tissue researchers define their work. As Clarke and Fujimura show, tools are essential elements of the work situation.[10] Just as it is crucial to focus on the tools of work, it is also important to address the objects around which work is organized and which form the core of what the work is about.

An important aspect of understanding work objects requires insisting on their situatedness. Although this conceptual framework encompasses the contexts in which work objects exist, it specifies the parameters of context in significant ways. Like tools, work objects are *always* located in practices which are themselves embedded in broader domains.[11] The situatedness of work objects within concrete practices and sites has important consequences for analysis. Most significantly, the context provides a social frame of reference which shapes the meanings actors attribute to work objects. Because human actors are also located in these sites, they bring to their work certain interpretations and perspectives. Thus the perceived symbolic nature of work objects is shaped in key ways by their embeddedness in particular social and cultural domains. This is the Meadian perspective on social objects. Yet the material character of work objects, their obdurate physical nature, also becomes conjoined with their symbolic character to mold both the contexts in which they are situated and the organization of work practices.

How might this concept be useful in approaching experimental fetal surgery as a sociological problem? Focusing on the fetal work object enables a framing of the question as such: *What does it take to access the fetus?* This allows for an analysis of social, cultural, political, material, technical, and other factors involved in creating a

---

[10]Other elements of the situation include workplaces, workers, representational entities such as theories and models, work organization, sponsorship, regulatory groups, audiences/consumers of work, and so on (Clarke and Fujimura 1992b).

[11]See Berg (1995) on the localization of tools in space, scope, and rationale.

new subject, the unborn patient, out of embodied, naturalized fetuses. In other words, it allows for analyzing the many layers that must be breached to reach the fetal patient. Layers of the pregnant woman's body--skin, tissue, fat, muscle--are peeled away, as are layers of clinical conventions, cultural meanings, and political resistance. Moving outward from the fetal work object, pregnant women represent the closest layer beyond which lies the elusive fetus. Throughout this dissertation, questions are raised and answered about ways in which pregnant women are construed as maternal work objects by others in fetal surgery and about women's own experiences. It is my contention that without pregnant women's bodies, subjectivities, and interactions with other participants there would be no enterprise of fetal surgery and no fetal patient.

Another analytical layer represents the social and technical relations of medicine which enhance access to the fetal work object. These include physicians' interests and desires, intraprofessional conflict over definitions of work objects, surgical and monitoring technologies, and so on. At this level, questions about maternal and fetal representations, as well as relationships between medical knowledges and practices, are addressed. Local institutional arrangements, such as fetal treatment programs are analyzed. Moreoever, the broader layers of social relations within which both pregnant women and medical practices are embedded are considered. Here questions can be asked and answered about relationships between fetal surgery and the politics of reproduction, the social and economic relations of medicine, and health policy issues.

Although useful in organizing an analysis of fetal work objects, to speak of "layers" as if this analytical model resembled concentric circles may be somewhat misleading. The actual practices of experimental fetal surgery reveal that these bodily and symbolic layers are overlapping, messy, and mutually constitutive, more ripe, pungent onion than flat, two-dimensional image. The value of this approach lies in using the material aspects of pregnancy, central to the contested nature of fetal work

objects, to formulate an analytic scheme. By focusing on fetuses as embodied and material, I address questions about how, why, and under what conditions the "unborn patient" as a new ontological subject emerges as an artifact of biomedical and technoscientific work. What *does* it take to get to the fetus, in a material, technical, social, and cultural sense?

Technofetuses and Technomoms: Working on Fetuses and Pregnant Women

This dissertation is principally concerned with work objects in technoscience and medicine, the domains in which a particular set of fetal practices is carried out.[12] Of the wide range of work objects in fetal practices, of most interest for this analysis are fetuses and pregnant women. Attempting to discern how fetuses and women are transfigured in fetal practices is not meant to suggest that there is a pure, natural version of pregnant women and their fetuses that exists prior to social meaning and context. Yet fetuses and pregnant women in science and medicine are, like many other entities in these domains, inscribed technologically, making them different entities than fetuses and pregnant women in other domains. For example, the dead (and recently refurbished) human fetuses on display in glass jars at Chicago's Museum of Science and Industry may represent different meanings than fetuses in fetal surgery, although both may invoke reproductive politics (Casper 1995). How is it possible to make sense of fetuses and pregnant women as they are embedded in different types of practices and contexts? In order to analyze the technical characteristics of fetal and maternal work objects, I have further refined my definition of fetal and maternal work objects to construct two new analytical entities: *technofetus* and *technomom.*[13]

---

[12]See Casper (1995) for a cyborg analysis of additional fetal practices, including ultrasound and other prenatal diagnostic technologies, post-mortem maternal ventilation, fetal tissue research, fetal wound healing, and fetal therapies. Other fetal practices include abortion, women's emotional and physical work in pregnancy, and so on.

[13]See Casper (1995) for an elaboration of this argument.

In fetal surgery, fetuses are diagnosed via ultrasound, chorionic villus sampling, fetoscopy, fetal blood sampling, and other technologies. In addition, during surgery the fetal patient is monitored with a radio telemeter connected to a Macintosh computer on which fetal indicators appear. After surgery, the fetus continues to be monitored via the pregnant woman, who often has a catheter inserted into her abdomen to provide ongoing continuous access to the fetus. In fetal tissue research, fetal material is constructed both discursively and materially as a research tool and a therapeutic technology. In many respects, fetuses--or, more accurately, fetal parts--are technologized through the practices of fetal tissue research. In fetal physiological and wound healing research, fetuses are (re)constructed as work objects using a variety of technologies, including the fetuses themselves and/or parts of fetuses (see Chapter 4). In short, fetuses in technoscience and medicine are highly technologized work objects, as well as labor- and capital-intensive objects of investment.

Pregnant women are also varyingly constructed through diverse technical practices as sites of production for fetal materials; as technologies with which a Fetal Intensive Care Unit may be equipped; as organic, recalcitrant capsules which must be surgically opened in order to expose the fetal patient; as "heart-lung machines" which must be monitored, managed, and disciplined to "protect" the fetus; and so on. These maternal constructions, like fetal constructions, are highly technologized and contested. Ironically, in the high-tech environment of fetal surgery, practitioners routinely and generically refer to pregnant women as "Mom," invoking images of home and apple pie. But pregnant women in fetal surgery are not like other mothers; they are rather uniquely technologized and compromised objects of medical work. Their transformation from pregnant women into maternal work objects for enhancing fetal treatment carries with it a number of cultural, political, and clinical risks and implications. (See Chapter 6 for a fuller discussion of this process.)

The material aspects of these unique, embodied work objects shapes the organization of fetal research and treatment practices. Within fetal practices, fetal and maternal work objects may be distinct entities or they may be corporeally connected in pregnancy. When they are connected, as in fetal surgery, fetuses become difficult work objects in that access is impeded by the pregnant woman's body in which the fetus is located. Accessing the fetal work object often means getting inside or opening another work object: the pregnant woman. If fetuses are disembodied into fetal parts, as in fetal tissue research, they must first be obtained from pregnant female bodies, again raising accessibility issues. Thus, the material and corporeal aspects of the maternal/fetal relationship present many challenges to working on pregnant women and their fetuses. Analyzing fetal work objects brings into relief the nature, scope, and organization of the work practices in which they are embedded.

Moreover, fetal practices exist within a wider social, political, cultural, and economic milieu in which fetuses are particularly controversial. As cultural and political symbols, fetuses are invested with diverse, often conflicting meanings and are claimed on behalf of different, usually conflicting interests. The contested nature of fetal work objects in the U.S. renders *all* fetal practices problematic, regardless of their purpose or organization. Whether the practice in question is fetal tissue research or fetal surgery, links to reproductive politics frame these practices in significant ways. While practitioners who work on fetuses may seek to avoid connections to abortion, and they almost always do, the material nature of the work makes this almost impossible. This is not to apply a biologically reductionist framework to maternal/fetal relationships, which is quite problematic from a feminist perspective.[14] Rather, it is to insist on the significance of the material, corporeal relationships *and* the social relationships between pregnant women and their fetuses (Rothman 1989). It is also

---

[14]See Morgan (1995) for a useful and nuanced discussion of feminist research on fetuses and the maternal/fetal relationship.

to recognize that maternal/fetal relationships are mediated by the social and political context in which they exist, a condition which impacts work on fetuses in especially charged ways. In the late twentieth-century U.S., human reproduction is a social problem, which renders fetal practices controversial as well.

The term *technofetus* makes concrete the nature of the domains in which technologized fetal constructions are enacted and deconstructs the monolithic "fetus" deployed across domains.[15] The term undergirds my argument that the "unborn" patient is *made*, not "born again" as Harrison (1991) asserts. The term *technomom* signifies the ways in which maternal subjectivity and materiality are constructed through fetal practices and deconstructs the generic "Mom" used by fetal practitioners. Neither term is meant to imply that technologization is necessarily negative; indeed, these concepts may provide ways of understanding how women use technologies to enhance their reproductive choices. Rather, they provide an analytical tool with which to examine the contested, political nature of heterogeneous fetal and maternal constructions and practices in technoscience and medicine. These terms are "sensitizing concepts" (Blumer 1969) which draw attention to the ways in which ostensibly "natural" objects are transformed through various kinds of medical work and technoscientific investment into other kinds of objects imbued with social meaning: patients, research subjects, tools, and materials, and so on. Further, both terms situate fetal and maternal work objects not only within domains of practices, but also within the broader context of reproductive politics as these have been transformed technologically (Stanworth 1987).

Both these entities, *technofetus* and *technomom*, will surface regularly throughout this dissertation in various analytical forms. Below, I explore the use of fetal work objects, or technofetuses, in experimental fetal surgery and fetal tissue

---

[15]As Morgan (1995:18) points out, "as the contexts for fetal discourse proliferate, it will be increasingly clear that we cannot talk about 'the' fetus but rather need to talk about a diversity of fetuses which carry with them a multiplicity of overlapping meanings."

research, focusing on how they are defined and used as well as on implications for maternal work objects. It is here, in the technologized and capital-intensive worlds of biomedicine and technoscience, that fetal and maternal bodies and subjectivities are constructed, molded, and transformed into technofetuses and technomoms. First, however, it is important to lay out the history of controversy over fetal work objects which has shaped the development of fetal surgery and especially fetal tissue research.

The Historical Political Context of Fetal Research in the U.S.

Not all social conflict over human fetuses occurs among pro-choice and anti-abortion activists warring in the streets. Much controversy occurs at the less visible but no less heated institutional level of policy, where the relationship between fetal work objects and reproductive politics is hotly debated. Although fetal research has been conducted in the United States since the 1930s (Gold and Lehrman 1989; Greely, Hamm et al. 1989), contemporary political controversies over fetal research and treatment are rooted in the fetal tissue debates beginning in the early 1970s.[16] As Maynard-Moody (1984, 1995) has argued, those early debates were in part embedded within broader historical concerns about the use of human subjects in research generally, particularly those generated by Nazi scientific experimentation of the 1940s (Proctor 1988).

Policy makers in the United States were heavily influenced during the early 1970s by Great Britain's Peel Report, issued in 1972, which laid the foundations for ethical decisionmaking around fetal tissue research. Between 1972 and 1973, guidelines for tissue research were debated within the National Institutes of Health (NIH) and the Department of Health, Education, and Welfare (HEW). When the

---

[16]For a more comprehensive overview of this controversy, see Maynard-Moody (1984, 1995), Stith-Coleman, (1993), Institute of Medicine (1994), and Langston and Palfreman (1995).

Washington Post leaked details of the proposed guidelines to the public, the first wave in a series of controversies over fetal tissue crested. Public outcry in the form of wide media coverage and demonstrations at NIH led to revised guidelines and a ban in 1974 on controversial forms of fetal research. In accordance with the ban, the National Research Act of 1974 provided for the establishment of the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, which was to study the history, extent, purpose, and uses of fetal tissue research (Maynard-Moody 1984, 1995; Gold and Lehrman 1989). In July 1975, the Commission completed its study and recommended that fetal tissue research could continue as a scientific and clinical pursuit if it adhered to ethical guidelines, namely that no harm come to fetuses used in research and that the research benefit fetuses. Although this signaled the end of the first wave of controversy in the U.S., it was merely the calm before the storm.

Fetal tissue research continued largely unencumbered by direct political intervention until 1982, when a second wave of controversy surfaced. Representative William Dannemeyer proposed an amendment to the NIH Reauthorization Bill that would have prohibited federally sponsored research on fetuses. Although the amendment cleared the House, it never came before the Senate and thus never became part of the NIH Reauthorization Bill (Maynard-Moody 1984, 1995). An opposing amendment proposed by Representative Henry Waxman was passed instead, effectively reinstating previously existing federal regulations allowing limited forms of fetal tissue research. Debates among policy makers during this wave of the fetal tissue research controversy largely centered around issues similar to the earlier debates. Supporters of the Dannemeyer amendment employed images of Nazi experimentation on the helpless and argued that "pregnant women who have chosen abortion have abdicated their parental right to approve research affecting their fetus" (Maynard-Moody 1984:227). Opponents of the amendment portrayed it as ideological, grounded in moralistic politics and antithetical to scientific progress. This

wave of the fetal tissue controversy subsided in 1985, when Congress passed a three-year reauthorization of NIH that included a limited moratorium on federally-funded fetal research but not an outright ban on such research. The legislation also created a Biomedical Ethics Board charged with investigating the "nature, advisability, and biomedical and ethical implications of exercising any waiver of the risk standard within the regulations on fetal research" (Gold and Lehrman 1989:9). Thus, with the moratorium in place at NIH, fetal tissue research again became submerged as a contentious political issue until it reemerged in 1988.

Prior to the 1988 NIH Reauthorization Bill, officials at the Institutes submitted a request to Assistant Secretary of Health Robert Windom seeking approval for funding of fetal tissue transplantation in an adult Parkinson's patient (Gold and Lehrman 1989; Palca 1989; Gershon 1990b; Langston and Palfreman 1995). In March 1988, Windom ordered a special NIH panel to review fetal tissue transplant research and imposed a temporary moratorium on the use of fetuses from elective abortions in federally-funded research pending recommendations of the panel. The NIH Human Fetal Tissue Transplant Research Panel concluded in late 1988 that fetal tissue research was "acceptable public policy," provided that certain ethical guidelines were followed, and recommended lifting the moratorium (Leary 1988; Gershon 1990a). In January 1989, NIH Director James Wyndgaarden forwarded the Panel's report and recommendations to Assistant Secretary of Health Windom, where no action was taken until the end of President Reagan's term in office (Donovan 1990). In fact, no action was taken until one year into President Bush's term, when, in November 1989, Secretary of Health and Human Services Louis Sullivan extended the moratorium on fetal tissue research indefinitely, despite the 1988 recommendations (Editor 1989; McGourty 1989; Palca 1989; Langston and Palfreman 1995). Sullivan extended the ban with the publicly stated rationale that permitting fetal tissue research would increase the number of abortions performed in the U.S. (McGourty 1989), thus directly

linking the fetal work object to reproductive politics. That ban expressly prohibited federal *funding* of fetal tissue research in which fetal tissue from *induced* abortions is transplanted into human patients (Palca 1989; Healy 1991); it did not prohibit fetal tissue research per se.

In spite of the relative longevity and robustness of the ban on federally sponsored fetal tissue research, it did not go unchallenged by opponents clearly invested in fetal work objects. For example, the Parkinson's Disease Foundation and the Association of American Medical Colleges threatened to sue the U.S. administration over the legality of the ban on the use of federal funds (Gershon 1990b; Gershon 1991). Linking fetal tissue research to improvements in Parkinson's patients was a particularly strategic move by scientists to wrest their research out from under the paralyzing thumb of the Federal government (Langston and Palfreman 1995). In addition, the American College of Obstetricians and Gynecologists (ACOG) and the American Fertility Society (AFS), increasingly frustrated by the Federal government's failure to open up fetal tissue research to public debate and assume a "leadership role," established the National Advisory Board on Ethics in Reproduction in 1991 (Gershon 1991; Hilts 1991c). This private advisory group was created to establish ethical guidelines for reproductive and fetal tissue research. It is financed and administered by the two medical societies and is comprised of doctors, scientists, ethicists, lawyers, and public health advocates. According to Ryan of the ACOG, "research on fetal tissue and reproductive technology is sustained and will continue with or without government regulation...the time is ripe for a private group to shoulder the task of setting standards to ensure that it is scientifically and ethically sound" (in Gershon 1991:184).

The 1992 transition from the Republican era of Reagan and Bush to the Democratic administration of Clinton and Gore brought significant changes in fetal research policy. While the abortion issue continues to occupy a unique place in U.S.

politics, President Clinton has consistently emphasized his support for abortion rights despite his willingness to acquiesce on issues such as parental notification for young women. He has also portrayed his administration as progressive in the realm of science and technology, making research a central component of his vision. It was not surprising when shortly after his inauguration Clinton lifted the 1974 ban that had prohibited federal funding of fetal tissue research in which tissue from induced abortions was transplanted into human patients.[17] In doing so, he seemed to demonstrate both his resistance to political pressure from the Right and his avowed commitment to biomedical research. Indirectly, Clinton's action also legitimated the use of fetal work objects in federally-sponsored research.

Yet the 1994 elections resulting in a Republican majority in Congress unleashed a rightward shift in American politics. One month after the elections, in a rather stunning turnabout, Clinton ruled out using federal funds to support research on human *embryos*, as in infertility studies. Following an NIH recommendation that the government support research on human embryos outside the womb, Clinton quickly issued a directive prohibiting the use of federal money. According to a White House statement, Clinton felt "strongly" that human embryo research raised "profound ethical and moral questions" (New York Times 1994). Had he accepted the NIH recommendation that federal funds be used for these purposes, his administration would likely have become a target of conservative groups. The directive clearly (and sadly for some) indicated that Clinton was no less malleable in the face of vocal and organized right-wing anti-abortion politicking than his predecessor had been. Yet by shifting his position from the earlier order lifting the moratorium on fetal tissue research, Clinton found himself enrolled by opponents in ways he may not have anticipated. After Clinton's statement appeared, the National Right to Life Committee

---

[17]Executive Order 58 FR 7468. Clinton also ordered that the National Institutes of Health develop guidelines for fetal tissue transplantation and fetal research (Institute of Medicine 1994).

issued their own: "President Clinton, after meditating on the recent defeat of ranks of pro-abortion incumbents, has suddenly displayed a spark of respect for the sanctity of innocent human life. We hope that spark will grow" (New York Times 1994).

In sum, the fetal tissue research controversy has been pursued in the U.S. by diverse sets of actors with multiple and conflicting interests, political commitments, and goals. Throughout the history of this controversy, scientists, anti-abortion activists, and others have pursued their own interests and aims with respect to fetal work objects. In the early phases of the controversy, scientists were able to significantly influence policy in the direction of their interests, allowing fetal tissue research to continue unencumbered by broader political considerations. However, the emergence of the fetus as a dominant cultural icon in the past decade and the consecutive terms in office of highly conservative administrations in the 1980s enabled the anti-abortion movement to manipulate the fetal tissue agenda in the direction of their own fetocentric interests. The ban on federal funding of fetal tissue transplantation research was a direct result of militant and aggressive lobbying by the anti-abortion movement, which consistently and effectively linked fetal work objects directly to reproductive politics. The reversal and subsequent partial reinstitution of the ban by Clinton serve as potent illustrations of the political nature of fetal research and the ways in which its fate has been linked to the ebb and flow of the U.S. political tide.

Next I comparatively discuss fetal surgery and fetal tissue research more directly, pointing to links between scientific research and the cultural politics of reproduction. What is striking about the fetal research dispute is that "therapeutic" research, such as experimental fetal surgery, has been somewhat insulated from controversy despite its focus on living fetal work objects still in the womb. High mortality rates notwithstanding, clinicians' claims that therapy is *beneficial* to fetuses garner enough legitimacy to offset the cloud of controversy that seems to perpetually

hang over fetal tissue research. The different ways in which human fetuses are used and construed across these different yet interrelated practices have important ontological, political, and clinical implications.

Experimental Fetal Surgery: Constructing the Fetus as a Patient

In contemporary experimental fetal surgery, fetuses are considered and treated as primary work objects.[18] They are the focus of an array of work practices and conventions, including surgery, research, technology production and use, and professional interactions. Through these overlapping practices, the fetus is constructed as a human subject in various guises, including patient, and is often assigned agency, consciousness, and personality. These constructions are in turn consequential for fetal surgeons' work practices, as well as for other actors in the fetal surgery domain, especially pregnant women.

Contemporary representations and practices of experimental surgery are grounded historically in early attempts to treat fetuses in utero. In the 1960s, erythroblastosis fetalis, a hemolytic (blood) disease, was considered a major problem faced by obstetricians. This condition results from Rh incompatibility between maternal and fetal blood and is characterized by excessive erythroblasts (or red blood cell precursors) in fetal circulation. Early therapeutic efforts were limited to delivery of affected fetuses prematurely, which "often converted what would have been a fetal demise into a neonatal death" (Pringle 1986:23).

The introduction of spectrophotometric analysis of amniotic fluid as a fetal diagnostic technology spurred interest in therapeutic technologies. William Liley, a pediatric neurophysiologist from New Zealand who has been called the "patron saint" of fetal medicine (Koop 1986), developed a technique of intraperitoneal transfusion, or

---

[18]Experimental fetal surgery will be described at greath length throughout the dissertation. Here I present an abbreviated overview for the purposes of this chapter.

transfusion via catheterization of tissues in the abdominal cavity, in 1963. This procedure enabled relatively safe and efficient maternal-fetal transfusions, making Rh incompatibility less threatening and decreasing mortality, at least where this technology is available and accessible. (This work is described at length in Chapter 3.)

What is striking about Liley's work, aside from the widespread application of his techniques in obstetrical practice, was his commitment to defining the fetal work object as a person and patient. In an article originally published in 1972 entitled "The Fetus as a Personality," Liley (1986) described fetal agency by presenting "a day in the life of a fetus." He suggested:

> we may not all live to grow old but we were each once a fetus ourselves. As such we had some engaging qualities which unfortunately we lost as we grew older. We were physically and physiologically robust. We were supple and not obese. Our most depraved vice was thumbsucking, and the worst consequence of drinking liquor was hiccups not alcoholism...Is it too much to ask therefore that perhaps we should accord...to fetal personality and behavior, rudimentary as they may appear by adult standards, the same consideration and respect? (Liley 1986:17)

Contradicting earlier pre-modern conceptions of the fetus as a passive *tabula rasa* in the uterus, Liley constructed it as "very much in command of the pregnancy" (1986:9). His account of fetal personhood is replete with action verbs: the fetus "guarantees" the success of pregnancy, "induces" changes in maternal physiology, "determines" the duration of pregnancy, "decides" which way he [sic] will present in labor, "learns" and "responds" to stimuli, and so on.

These representations of fetal agency are quite consequential for others involved in fetal treatment. One learns from Liley's account that women do almost no work in pregnancy; they are simply organic receptacles in which a very busy and determined fetus accomplishes a great deal. The pregnant woman in whose body the fetus is nurtured is reduced to a "suitable host," "the space and shape available to [the fetus]," "the walls of the fetal world," "a pregnant uterus," or "a plastic, reactive structure." As Liley's work illustrates, constructions of active fetal agency may render pregnant women invisible as human actors and reduce them to techno-maternal environments for the fetal patient.[19]

Two decades later, similar maternal and fetal constructions resurface in contemporary fetal surgery practices. Within a broader context of fetal treatments ranging from drug therapy and blood transfusions to "selective termination" where there are multiple fetuses, surgery is the most invasive treatment of the fetus and of the pregnant woman in whose body the fetus grows. Fetal surgery is currently limited to lethal conditions, such as congenital diaphragmatic hernia (CDH) and urinary tract obstructions.[20] The objective of fetal surgery is to repair damage in utero to save the fetus or to prevent life-threatening conditions from developing at birth. Statistics on fetal mortality are discouraging for fetal surgeons, pregnant women, and others. About 50% of fetuses die, while those who live are unlikely to be fully healthy and will *always* require postnatal treatment of some kind, often immediately after birth. Maternal mortality statistics are better; as one physician assured me, "we haven't lost a mom yet." Yet in terms of morbidity, the pregnant women's health status after

---

[19]An article in *Science* (Palca 1991) reported research that locates the mechanism for onset of birth in the fetal brain, suggesting that the fetal actor is still hard at work commanding pregnancy.

[20]Congenital diaphragmatic hernia (CDH) is a condition in which there is a hole in the diaphragm, causing fetal organs to migrate upward into the chest cavity and to impair lung development. Fetal surgery for CDH is designed to repair the diaphragm *in utero* and reposition the organs in the fetal abdominal cavity, thereby making room for subsequent lung development. Many fetuses with CDH die at birth; those who live and undergo surgery after birth generally have respiratory and other problems for the rest of their lives. Urinary tract obstructions, which may be caused by a number of factors, generally result in an excess build-up of fluid in the kidneys, leading to severe kidney damage and/or renal failure.

two cesarean sections and often several weeks of intensive clinical management may be severely compromised (Harrison and Longaker 1991).

In practice, fetal surgery involves opening a pregnant woman's abdomen via cesarean section, taking her fetus partially out and operating on it, closing and reinserting the fetus, and then closing and suturing the pregnant woman. Recall the graphic descriptions of fetal surgery from Chapter 1. Throughout the procedure, fetal surgeons are assisted by numerous other participants, including nurses, anesthesiologists, radiologists, and neonatologists. At any given time, there are between eight and fifteen individuals in the operating room (not including the fetus). Fetal surgery, like most medical practices, is a heterogeneous and collective enterprise. (These issues will be discussed more fully in Chapter 5.)

A significant aspect of fetal surgery is that there are two patients on the operating table: the pregnant woman and her fetus. However, the fetus is considered the primary work object, as illustrated by a number of specific practices. For example, all operations in the fetal treatment unit are videotaped for research and recording purposes. Taping usually begins once the surgeons are inside the woman's abdomen and ends when they have finished working on the fetus. This convention illustrates quite starkly who, or what, is perceived as the work object and what is defined as important and interesting work in fetal surgery.

Through an array of practices, the fetus is positioned as a (potential) person with human attributions. For example, in fetal treatment meetings at one institution fetuses are routinely referred to as "the kid," "the baby," and "he," all quite human--and gendered--identities. A major way in which fetal personhood is accomplished, moreover, is by constructions of the fetus as a *patient*. In fetal surgery, fetuses become patients worthy and deserving of treatment, a social attribution enacted in medical work (Zola 1973). Consider the following quote from Jack Nelson, a surgeon in the fetal treatment unit at Hilltop Hospital:

> [The fetus] is so viable as a patient that I'm willing to invest my life work in order to help that patient. We have 10 surgeons in the lab whose only focus the majority of the time is the fetus as a patient. We have obstetricians, there's probably a dozen of them whose focus is...the fetus as a patient. We have anesthesiologists, nurses. We're all operating on fetuses, trying our best to protect them.[21]

The emphasis on fetal patienthood is apparent in the Fetal Treatment Unit's plan to start a Fetal Intensive Care Unit (FICU) for post-treatment evaluation and management. According to surgeon Karl Hansen, the FICU would involve "a specific room and specific equipment to monitor the fetus." In response to my query about the role of the pregnant woman in a FICU, Nelson remarked, "A fetal intensive care unit would actually be a maternal intensive care unit, obviously." He stated on another occasion that a pregnant woman is "the best heart-lung machine available." These comments suggest that the pregnant woman may well be defined as part of the technology with which the FICU is equipped (see Chapter 6).

As the foregoing example illustrates, fetal constructions in contemporary surgical practices, like those articulated earlier by Liley (1986), exist alongside maternal constructions. The pregnant women in fetal surgery, often referred to simply as "Mom" by the practitioners, are treated as obstacles, recalcitrant bodies which must be surgically penetrated in order to reach the primary patient. This is vividly described in the field notes cited earlier, as well as in clinical literature on the subject (Harrison and Longaker 1991; Scheerer and Katz 1991). During and after treatment, the women are carefully managed, monitored, and controlled lest their actions and

---

[21]This comment raises the question, from what or from whom physicians are attempting to protect the fetus. Given the degree to which the discourse of maternal-fetal conflict permeates biomedical practices (Macklin 1990; Purdy 1990), one cannot help but wonder if it is pregnant women who are perceived as threats to their fetuses.

bodies cause irreparable damage to the fragile fetal patient. According to Jack Nelson, improving fetal outcomes "involves placing mom in an intensive setting, intensively monitoring as many parameters as we can, changing those things we can, and in essence applying a 100% effort."

In fetal surgery, then, practitioners have organized their work activities around a living fetal entity defined as the primary work object and constructed as a patient, person, and agent--in short, as "human." These fetal positions mirror similar constructions of fetuses in the realm of cultural politics and are consequential both for surgeons' work practices and for pregnant women. As with Liley's representations of active fetal agency, contemporary treatments erase maternal agency and position pregnant women as technomoms. This is quite different from how fetuses are positioned within fetal tissue research, discussed below.

Fetal Tissue Research: Fetuses as Research Tools and Therapeutic Technologies

Fetal tissue research is not a single enterprise but rather encompasses multiple scientific and biomedical practices in which fetal tissue is used as a work object. For example, fetal tissue is used in fetal physiological research, in the development of cell lines (Hana Biologics Inc. 1988), for transplantation into living tissue (Seiger 1989; Council on Scientific Affairs and Council on Ethical and Judicial Affairs 1990), and as a research tool in other scientific enterprises, such as the Human Genome Project (Fletcher 1990). Unlike experimental fetal treatments, in which the work object is a living fetus, fetal tissue research uses material from dead fetuses obtained from abortions, ectopic pregnancies, and other sources. As we saw, such research is often pursued against a backdrop of intense conflict generated by the perceived moral and cultural implications of fetal tissue research and by its location within the stormy arena of abortion politics. In navigating the turbulent sea of

controversy, scientists have constructed the fetal work object as a *research tool* and *therapeutic technology* useful for a range of practices, while simultaneously struggling to distinguish it from the abortion domain, where issues of humanity and life are salient.[22]

Why is fetal tissue so special? Fetuses are claimed to have several properties which make fetal tissue an ideal research tool and therapeutic technology. First, fetuses have a limited immune system which enables fetal tissue to be introduced into another organism's tissue with minimal adverse response from the host body. Fetal tissue also has tremendous growth potential and is remarkably biologically plastic and thus easily integrated into the physiological environment of other living materials.[23] Further, because fetuses develop in the protective environment of women's bodies, fetal tissue and organs are unlikely to be contaminated or pathological. Finally, fetal tissue is capable of being preserved and subsequently reanimated, such as in cryopreservation where it is frozen and then revived. For all of these reasons, fetuses are often described by scientists as the "gold standard" in cell transplantation (Redmond 1991) and are thus considered valuable work objects.

There are many ways in which fetal tissue is claimed to be beneficial. These include the establishment of fetal cell lines to provide model systems for studying cell differentiation and growth; replication of human viruses, which may be used to develop and test vaccines; screening of new pharmaceutical agents to determine teratogenicity (whether or not they create "monsters"); and treatment of clinical disorders, such as Parkinson's and Alzheimer's diseases, diabetes mellitus, and immunodeficiency disorders. Other *potential* therapeutic uses for fetal tissue include hematologic (or

---

[22]Association with abortion, which is itself highly controversial, virtually assures that science and technology in these domains will be contested (Clarke 1990). For these and other reasons, fetal tissue research and research on live fetuses are controversial domains and have been debated in the U.S. since the early 1970s in science, health, and policy arenas (Casper 1992). Of all the fetal tissue practices, transplantation research is considered most controversial and is the central focus of contemporary debates.

[23]These qualities raise provocative images of the fetus as Play-Doh™ or Silly Putty™, easily manipulated and shaped into all sorts of whimsical and serious constructions.

blood) disorders like acute myelogenous leukemia, in which abnormal cells occur in large numbers in various tissues and in blood circulation, and genetic disorders such as thalassemia, an inherited metabolic disorder which may cause anemia (Council on Scientific Affairs and Council on Ethical and Judicial Affairs 1990).

Fetal tissue transplantation practices are especially touted as important new approaches in biomedical therapy for Parkinson's, Huntington's, and Alzheimer's diseases and for diabetes. In the past few years, researchers in the U.S. and elsewhere have reported major advances in fetal tissue transplantation therapy. In 1992, for example, scientists presented evidence that fetal tissue transplants may alleviate Parkinson's disease symptoms. In two patients with brain damage, researchers implanted fetal cells directly into the patients' brains using a slender tube drilled into the skull (Kolata 1992).[24] In 1991, researchers reported a successful fetus-to-fetus transplant for treatment of a genetic disease. Fetal cells were transplanted directly into a living fetus while still in its mother's body; approximately six months after birth the new cells began to produce a necessary enzyme (Hilts 1991b). Such examples vividly illustrate material constructions of the fetal work object as a therapeutic technology and, in the latter case, as a patient.

As a research tool, fetal tissue is often connected to the continued viability and success of other technoscientific endeavors, such as the Human Genome Project (Kevles and Hood 1992). This is not insignificant, as the U.S. has committed $3 billion over the next 15 years to an international effort to map the human genome (Koshland 1989). According to ethicist Joseph Fletcher, the Human Genome Project is predicated on the necessity of conducting basic research "in the embryo and fetus to learn how genetic diseases begin and develop" (Donovan 1990:230). However, "because U.S. investigators are forbidden from studying human embryos, fetuses, and

---

[24]See Langston and Palfreman (1995) for a gripping account of research on Parkinson's disease and the role of fetal tissue transplantation in therapeutic efforts. Their account contains many similar descriptions of experimental transplantation treatments using fetal cells.

fetal tissue, they are forbidden from looking for treatments or cures for the very same genetic diseases they are committed to discovering" (Fletcher 1991:10).[25] Thus, as with fetal physiology, relative inaccessibility of the fetal work object in tissue research poses constraints on scientific practice.

Significantly, while defining the fetus as both a therapeutic technology and a research tool, American scientists have also attempted to distance themselves from the politically volatile issue of abortion. Because of the intense conflict generated by the abortion debates and resulting political sensitivity, scientists have sought to define fetal tissue research--and fetal tissue *qua* work object--as distinct and separate from abortion. Yet given the material significance of pregnancy and the origins of fetal tissue, often publicly articulated by anti-abortion activists, this has proved a difficult challenge. Since the early 1980s, when the fetus emerged as a significant cultural icon in abortion politics (Petchesky 1987), scientists have expended an enormous amount of energy arguing that fetal tissue research is not connected to or implicated by abortion politics, despite the almost universal use of fetal tissue from *induced* abortions in scientific research.

One strategy scientists have employed to distance fetal tissue research from abortion politics is to investigate alternative sources of tissue, such as genetically engineered fetal cell lines (Hana Biologics Inc. 1988, 1989, 1990). Some scientists suggest that with the administrative ban on funding and increasingly more effective contraceptive methods, it would also be "prudent to investigate the usefulness of spontaneously [as opposed to induced] aborted fetuses for transplantation" (Thorne and Michejda 1989). Others assert that spontaneous abortions, ectopic pregnancies, yolk sac tissue, placental tissue, and development of fetal cell lines might all be considered acceptable alternatives to using fetal tissue from induced abortions (Fung

[25]Given the fluidity with which the federal funding ban on fetal tissue research moves about, it would be useful to map intersections of fetal research with the Human Genome Project. Not only are fetuses used as materials in genetics research, but both genome researchers and fetal clinicians make claims about the potential benefits of prenatal gene therapy (Karson and Anderson 1991).

and Lo 1990). Still others look to non-human sources of fetal tissue, and hence to non-human fetal work objects. Researchers in the U.S. recently performed the first experimental cross-species transplant of brain cells, transplanting tissue from fetal pig brains into the diseased brain of a 59-year old Parkinson's patient (Saltus 1995).

There are, however, potential problems resulting from these alternatives to obtaining fetal tissue from induced abortions. Some scientists argue that tissue from spontaneously aborted fetuses or ectopic pregnancies might not be viable research material because it can remain in the womb for days or even weeks after the fetus dies, resulting in massive tissue degeneration (Palca 1992).[26] There is also some concern about whether spontaneous abortions and ectopic pregnancies would produce *enough* fetal tissue to meet researchers' needs. NIH officials estimate that about 2,000 tissue samples per year could be made available through proposed national tissue banks. This is significantly fewer than the approximately 1.5 million induced abortions each year in the U.S., about half of which could provide usable fetal tissue (Hilts 1992). Of course, use of RU486, itself the subject of much contestation (Clarke and Montini 1993), or a combination of methotrexate and misoprostol (Brody 1995), might reduce this amount considerably. These experimental abortifacients would allow women to have abortions in any doctor's office or potentially even at home, thus privatizing the disposal of fetal waste.

Another alternative to procuring fetal tissue from abortions is the production of genetically engineered fetal cell lines, or changing the nature of the work object, which also attracts its share of controversy and constraint. In addition to facing public opposition to genetic engineering, biotechnology companies involved in the production of synthetic fetal cell lines confront increased pressure from anti-abortion groups because human fetal cells must be used as prototypes. For example, in 1988 and

---

[26]According to Hogle (1993), in human organ procurement practices potential donors are often referred to as "'dead,' 'double-dead,' and 'triple-dead,' which translates as circulatory arrest, brain dead and 'dead-so-long-it-can't-even-be-used-for-tissues.'" In this framing, fetuses from spontaneous abortions and ectopic pregnancies would likely be considered "triple-dead."

1989, California-based Hana Biologics Inc. was "dedicated to the research and development of cell transplant technology" (Hana Biologics Inc. 1988:1, 1989). The company established "proliferation technologies" which enabled the formation of cell lines from central nervous system (CNS) "progenitor" cells. Hana's 1990 Annual Report detailed its continuing commitment to cell-based therapeutic approaches, yet also noted that "research into barrier technologies has enabled Hana to shift away from the use of fetal cells, which provided us with important basic information but proved a *difficult approach to commercialize*" (Hana Biologics Inc. 1990; emphasis added). With Hana's departure from the "progenitor proliferation technology" market, there are few, if any, companies in the U.S. working to develop fetal cell lines.[27]

Fetal tissue researchers have also sought to distance their work from abortion by formulating ethical guidelines to discursively and materially "insulate" these practices (Strong 1991). In conjunction with bioethicists, lawyers, and policy makers, scientists have pushed for recommendations that distinguish fetal work objects from reproductive politics. Guidelines suggest that a woman's decision to abort be kept independent of the decision to retrieve and use fetal tissue; that no economic benefits deriving from fetal tissue accrue to abortion providers, women who undergo abortions, or any other party involved with the exception of fetal procurement agencies;[28] that commercial use or sale of fetal tissue be prohibited; that physicians who perform abortions not be the same individuals who practice fetal tissue research; and that the Uniform Anatomical Gift Act (UAGA) be amended to prohibit the donation of fetal tissue from induced abortions to specific persons (Annas and Elias 1989; Greely,

---

[27]Research on fetal cell lines may be practiced at university-based laboratories, but I do not have sufficient data at this time to argue this point further.

[28]Hogle (1993) has analyzed the commodification of human biological materials and the market-oriented approach of organ procurement practices. As an exemplar of late-capitalist production processes, human organ procurement practices increasingly reflect economic needs, as in the institutionalization of donor management techniques designed to produce "prime, quality organs," procurement-effectiveness techniques, and concerns with product liability.

Hamm et al. 1989; Hillebrecht 1989). With the institutionalization of some of these ethical guidelines (e.g., in proposed legislation such as the Research Freedom Act and in state implementation of the UAGA) and their integration into local practice, scientists believe they have achieved a "practical separation of induced abortion and the subsequent use of human fetal tissue for the purposes of public policy" (Nelson 1990:447).

The construction of the fetal work object as a research tool and therapeutic technology, and its concomitant delineation/deletion from abortion politics, is consequential for other participants in these domains, especially pregnant women. Representations such as those described here bound and segment off the fetal work object from its source; this is the move to physical segmentation discussed in Chapter 1. Efforts to distinguish fetal tissue research from abortion in effect erases fetal tissue's material/maternal origins. Fetal constructions as deployed by scientists often fail to consider that it is women's bodies from which fetal tissue is removed and which provide the material work objects for the broader scientific endeavor of fetal research. Feminist legal scholar Janice Raymond criticizes this lack of attention paid to women and claims that "fetal tissue research and transplants make women into mere environments and containers for the fetus...More and more it is women who are expected to be altruistic with what issues from their bodies" (Hilts 1991a:B8).

Another potential yet little discussed consequence of such constructions relates to fetal tissue procurement practices and their impact on women differentially situated in American society. Given the market-driven approach of human organ procurement practices, feminist legal scholars have argued that the demand for fetal tissue may create a market in which certain groups of women will "choose" abortions for economic reasons. Taub states, "This is almost a variant on the Baby M thing; a way women could make money through reproduction" (Lewin 1987). This sentiment is echoed by Hillebrecht (1989), who predicts the emergence of a profit-motivated fetal

transplant industry in which women's bodies are mined and exploited for research materials.

As these accounts illustrate, the materiality of fetal work objects is consequential not only for scientists' work practices, but for other implicated actors as well. Anti-abortion groups protest constructions of fetuses as research tools and therapeutic technologies, and instead portray fetal tissue research as an illegitimate and immoral use of "the unborn." Feminists, legal scholars, and others strive to articulate connections between fetal tissue research and abortion practices as a means of preventing erasure of the material origins of fetal work objects. By situating the fetus outside of domains in which contestations over life, humanity, and agency are central, fetal tissue researchers seek to side-step the controversial issues raised in abortion politics. However, although fetal tissue *qua* material facilitates research, therapy, and other practices, it also links such practices to abortion and generates political controversy. Fetal tissue research is thus both enabled and constrained by the materiality of fetal work objects--an ongoing tension unlikely to abate.

Situating Work Objects: Global, Local, and Positions In-Between

I began this chapter with a theoretical description of work objects, laying out core parameters of this concept and guidelines for its use in empirical research. Among its many advantages is that it serves as an analytical tool with which to examine how different types of practices may be linked by a shared work object. It enables a careful examination of how the seemingly disparate domains of culture, politics, technoscience, and biomedicine are woven together in the social fabric. By focusing comparatively on experimental fetal surgery and fetal tissue research, I have offered an analysis of the local, contingent, and consequential nature of work objects within these domains. Both fetal surgery and fetal tissue research share a conception of the fetus as a particular type of biological entity, a global archetype of the "natural,"

human fetus imbued with particular qualities and characteristics. Yet each relies on and constructs different definitions of the fetus as a work object, or localized versions of *technofetuses*, in which these qualities and characteristics are fluid. As we saw, the fetus is simultaneously positioned as a patient, person, and agent, *and* as a tool, technology, and biomedical therapy. All of these fetal representations at the margins of humanity connect to cultural and political conceptions of the fetus in different yet consequential ways. Both fetal surgery and fetal tissue research resonate with the politics of reproduction, one by shifting what counts as a human fetus and the other by invoking the specter of abortion.

I also discussed maternal work objects in these domains, focusing on how pregnant women are shaped and implicated by work on fetuses. As illustrated in the discussion of the Fetal Intensive Care Unit, emphasis on the *fetal* patient tends to detract from the *maternal* patient, *as if* they were distinct entities. But clinical practices aimed at pregnant women in fetal surgery, such as intensive care, are claimed to enhance fetal well-being precisely *because* a pregnant woman and her fetus are physiologically connected. Ironically, then, where fetuses are defined as fully human, imbued with both personhood and agency as in experimental fetal surgery, pregnant women are configured as technologies to be managed, or passive fetal environments, in ways which diminish their humanity. This is quite different from fetal tissue research, where the procurement of materials via abortion practices links dead, disembodied fetal work objects to pregnancy. Anti-abortion groups in the U.S. focus on this linkage to claim the essential humanity or "life" of fetuses and fetal parts, while scientists simultaneously attempt to de-emphasize the abortion connection and construct fetuses as merely tools and technologies. Thus, just as fetuses are shaped by a range of practices in science and medicine, so too are pregnant women, or *technomoms*, configured differently across the practices discussed here.

I want to conclude by suggesting that global conceptions of fetuses and pregnant women exist simultaneously alongside local constructions. In other words, fetal practices in science and medicine are organized both around the "public" fetus (Taylor 1993), representing fetal ontologies shaped by social criteria such as personhood and agency, and around fetal work objects defined and used in various ways by scientists and clinicians. Pregnant women are varyingly construed as "Moms," invested with cultural meanings about what constitutes good mothering, and as maternal work objects representing material opportunities and constraints for scientists and clinicians. All of these diverse representations and uses exist within the broader context of reproductive politics infusing contemporary American society. This argument recognizes that fetal and maternal work objects are defined both materially and symbolically. They both enable and limit or impede certain types of work practices, while they are also simultaneously shaped by these practices. These tensions and patterns will resurface again and again in the remainder of this dissertation as I explore different dimensions of experimental fetal surgery.

Chapter 3

BREACHING THE WOMB: HISTORICAL EMERGENCE OF THE FETAL SURGICAL PATIENT

"Now that the beginning and the end of life have been identified as the major biological frontiers of the twenty-first century, we need the perspective of history to help us wrestle with these unclear boundaries."
(Stafford 1991:211)

"They were nothing more than people, by themselves. Even paired, any pairing, they would have been nothing more than people by themselves. But all together, they have become the heart and muscle and mind of something perilous and new, something strange and growing and great. Together, all together, they are the instruments of change."
(Hulme 1983:4)

Contemporary fetal surgeons, in recounting the origins of their work, often describe Sir A. William Liley (1929-1983) as the "father of fetology."[1] Although Liley may well be identified as the primogenitor of the fetal patient, this origin myth too closely resembles the "great men" approach to historiography.[2] This is not to suggest that Liley was not a great man nor central to the story of fetal surgery; his many colleagues and friends certainly believed that he was. Rather, it is to insist on a historical record which recognizes the multiplicity of actors and practices involved in crafting fetal patienthood. The history of fetal surgery is the story of many physicians, scientists, researchers, pregnant women, human fetuses, animals, and technologies arrayed across time, geography, and political change. It is a tale of arduous medical

---

[1] Liley provided the "Foreword" to *The Unborn Patient* (1983), the "bible" of fetal diagnosis and treatment. Underneath his reprinted contribution in the second (1991) edition, the editors wrote "Sir William Liley, pioneer in fetal treatment and eloquent advocate for the fetal patient, died in June 1983. He will be sorely missed."

[2] See Clarke (1986:3, 1996) for a discussion of key issues in the historical sociology of science. As she points out, most science studies approaches seek "to avoid the internalist and idealist pitfalls of 'great men make creative discoveries in social vacuums' approaches to the sociology of science. Instead there is an attempt to elucidate the social and material worlds in which scientists conduct and produce their work; some analysts also attempt to specify these in relation to the knowledge generated itself."

work and scientific research, but also one of serendipity, of talented and well-connected people being in the right places at the right historical moments. Drawing on archival and related research conducted in New Zealand, Puerto Rico, and key U.S. locations, this chapter explores the historical roots of fetal surgery.[3]

In what follows, I recount the story of the historical emergence of the unborn patient through key fetal work practices in biomedicine. Unlike much medical historiography, which tends to focus on people or ideas as analytic objects of inquiry, my account attempts to follow the work itself.[4] I examine the corpus of work which shaped fetal treatment historically, including basic research, technological innovations, and clinical practices. By following the work required to transform fetuses into patients, I chart the historical configuration of an array of heterogeneous entities involved in this domain, including human actors. What emerges from this strategy is a picture of the complexity of this work, including but not limited to a recognition of the central roles of certain key actors, such as Liley.[5] A limitation of following the work is that certain actors are not visible, although this is a problem shared by all historical research. This is especially the case with the pregnant women patients, who are discussed in others' accounts but who do not appear as active participants in the existing historical record. In this account, I have attempted to at least represent all of the actors with commitments to the work of making the unborn patient even where archival material and access to other resources was sparse.

In this chapter I first introduce three key, interrelated figures active in fetal research and treatment in the 1960s: Vincent Freda, Karliss Adamsons, and William Liley. I then discuss the significance of Rh disease in the history of fetal treatment as

[3]The history of fetal surgery could easily fill an entire volume, and would be a worthy and necessary project for historians of medicine and science. I found it difficult to condense the material presented in this chapter from the rich and voluminous amount of data I collected through interviews, archival research, clinical documents and patient records, medical and scientific literature, and secondary sources.

[4]See Reverby and Rosner (1979), Brieger (1980), and Rosenberg (1988).

[5]In the history of medicine and science, there have always been central famous people In part, this is due to the organization of science and biomedicine which shapes who has access to the resources necessary to build a scientific or medical career with historical resonance (Latour 1983).

an impetus for the development of new medical techniques focused on the fetus. Next, I explore the pioneering efforts in New Zealand of Graham Liggins, who developed non-surgical fetal treatments, and of William Liley, renowned for developing a key surgical technique, intrauterine transfusion, for accessing the fetal patient. In particular, I focus on the collective medical and scientific work undergirding the emergence of these techniques and their role in crafting fetal patienthood. I then examine the relationship between Liley's political activism and his professional life, mapping connections between his anti-abortion position and his advocacy on behalf of the fetal patient. Moving on to New York and Puerto Rico, I discuss the emergence of open fetal surgery in animals and humans through the work of Freda, Adamsons, and their colleagues. I explore both the experimental underpinnings of these innovations as well as their relationship to reproductive politics. I conclude with a discussion of the analytical importance of work objects in situating these historical practices and a reexamination of the historiography of fetal surgery.

Working and Networking: Columbia University, New York City, 1964

The 1960s were a watershed decade in fetal diagnosis and treatment. In 1964, three major figures in the history of fetal surgery spent a fruitful year together at Columbia University in New York City. Continuing work that each of them was already engaged in, these medical men pursued a collaborative enterprise with consequences that have reverberated through history. The work they accomplished, and the important connections they established with each other, were vital elements in the making of the unborn patient.

Vincent Freda was a young obstetrician engaged in Rh research at Columbia University. Although trained in clinical obstetrics, he was deeply interested in immunology and blood, and forged ties with others in this field. Building on fetal physiological research and advances in immunology of previous decades, researchers

like Freda pursued the vexing problem of Rh disease hoping to eradicate it. Concurrently with a group of researchers from Liverpool, in the early 1960s Freda and his colleagues developed anti-D immunoprophylaxis, the Rh "vaccine," which drastically reduced the number of fetal and neonatal deaths from Rh hemolytic disease.

Karliss Adamsons was also a young obstetrician working at Columbia during this period. Born in Switzerland, Adamsons received his medical training in Germany, did a brief stint at Harvard, and then fulfilled a five-year residency at Columbia. During the last years of his residency, he became interested in fetal physiological problems related to cerebral palsy. He began traveling regularly to Puerto Rico to work with William Mendel, who managed a large primate colony in San Juan and was engaged in neurological research on monkeys. One of the striking serendipitous findings of his work on primates was how tolerant the monkey fetus was of intrusion. After finishing his residency in 1961, Adamsons spent several months continuing this primate research, returning to New York periodically to participate in the Rh efforts. It was during this period that he and Freda, building on the monkey experiments, attempted open fetal surgery in human patients, with mixed results.

William Liley, on the heels of his recent success in pioneering intrauterine transfusion for Rh disease in fetuses, moved his family from Auckland, New Zealand to New York City in 1964. Liley brought with him not only an understanding of the mechanisms of intrauterine transfusion, but also a wealth of knowledge about Rh disease based on years of research and clinical care at National Women's Hospital in Auckland. Where Freda's scientific research was aimed at finding a way to *prevent* Rh disease, the transfusion efforts developed by Liley were designed to *treat* fetuses. It is for this work, treating fetuses still in the womb, that Liley is considered the "father" of fetal surgery.

In 1964, then, Columbia University became a "hotbed" of fetal research and treatment. Gathered in one place at one historic time, Freda, Adamsons, and Liley

merged their talents, ideas, and ambitions into the joint enterprise of crafting the fetal patient. Yet before and after this period, there were other sites where medical and technoscientific work on fetuses was pursued by these and other actors. It is to these other places and practices which I now turn, beginning with a discussion of the importance of Rh disease in the history of fetal treatment.

The Significance of Rh Disease in the History of Fetal Treatment

Although there are many diseases and defects which lead to fetal and neonatal deaths, hemolytic disease resulting from Rh incompatibility is especially important in the origins of fetal treatment.[6] The Rh factor is a thin coating of chemicals that surrounds the red blood cell. About 85% of people have this coating, and their blood is called Rh-positive. Those with only a partial coating or with no coating on their red blood cells are called Rh-negative. People with Rh-negative blood cannot tolerate Rh-positive blood. During pregnancy, problems most often arise when the woman is Rh-negative and her fetus is Rh-positive, although there are other blood combinations which can be dangerous. In Rh disease, the woman's Rh-negative blood destroys the Rh-positive fetal blood by creating antibodies against it. When this happens, and the antibodies begin to filter across the placenta to the fetus, the fetal bloodstream begins producing red blood cells at an accelerated rate to replace the blood cells destroyed by the maternal antibodies. Because red blood cell production is increased, the cells are only partly formed; these are called *erythroblasts* to distinguish them from normal red blood cells which are called *erythrocytes*. This process eventually leads to anemia, jaundice, erythroblastosis, and, quite often, fetal demise.

Hemolytic disease has been of interest to an array of researchers not only because of its unique properties, but also because of the context in which it occurs:

[6]The information presented here on Rh disease is taken from a variety of sources, including unpublished talks and articles found in the collected papers of William Liley and some published articles (Liley and Boylan 1965; Liley 1968, n.d.c, n.d.b, n.d.d; and Zimmerman 1973).

pregnancy. The human body under normal circumstances manufactures biochemical substances called *antibodies* to fight foreign invaders, such as viruses or bacteria, called *antigens*. One of the most interesting physiological features of pregnancy is that a pregnant woman and her fetus exist in a state of *parabiosis* despite their genetic difference. That is, as Liley (1980a) argued, "Mother and baby are inevitably immunological foreigners because the baby inherits exactly half his tissue compatibility and blood group genes from his father." Yet the pregnant woman's body does not usually reject the fetus as a foreign invader. This is because the body's normal defense systems are "on hold" during pregnancy. The fetal intruder is protected from expulsion by the *trophoblast*, a thin layer of tissue forming the outer surface of the placenta and separating the pregnant woman's bloodstream from that of her fetus. The trophoblast, however, is a permeable membrane and antibodies can pass from the pregnant woman to her fetus, often with benefits to fetal and neonatal health. For example, babies who have never been exposed to measles or chickenpox enter the world with the temporary protection of their mothers' antibodies against these diseases circulating through their bloodstream. The trophoblast and its osmotic properties become problematic only when the antibodies a fetus receives from its mother across the placenta are dangerous, as in hemolytic or Rh disease.

Prevention and treatment of Rh disease in fetuses was a major medical and scientific goal in the 1960s. However, until hemolytic disease could be prevented and/or cured, it first had to be understood in terms of its pathology and nosology. As Zimmerman (1973) argues in his lively history of Rh disease, in the 1930s there was not one disease but rather several different conditions based on similar symptoms: hydrops, jaundice, anemia, and erythroblastosis. Eventually, through combined research in immunology, pathology, and serology, these four disorders came to be associated with a new disease: hemolytic or Rh disease. The classification of these

symptoms into the "modern" condition called hemolytic or Rh disease was closely interwoven with scientific efforts to discover ways of preventing and curing it.

Approximately one in 200 pregnancies are thought to be complicated by Rhesus sensitization in Caucasian populations. Prior to WWII, most Rh-negative women had little hope of delivering a healthy baby. Once a woman produced antibodies in response to Rh incompatibility in one pregnancy (whether or not it came to term), they were present for life and subsequent pregnancies were at increased risk for hemolytic disease. As Liley once wrote in a letter, "Once you have them, there's nothing we can do about them. Antibodies have long memories." The robustness of Rh disease meant that physicians pursued a multi-strategy prophylaxis scheme, including taking careful histories of a woman's previous blood transfusions, identifying blood type (A, B, O) and Rh-factors for all antenatal patients, screening patients for antibodies, and determining the husband or partner's Rh factor. Liley once summarized management of hemolytic disease as such: "Reassure everybody; trust nobody; and hope for the best, by all means, but prepare for the worst. There is little margin for error."[7]

Despite this early grim picture, from the 1930s to the 1960s a number of medical treatments were developed to treat Rh-affected babies, rendering the disease much less threatening to fetal and neonatal mortality. First, with the development of more sophisticated blood banking procedures in the 1930s and 1940s, and better methods for screening antenatal patients, it became possible to avoid transfusing mismatched blood into pregnant women. Second, the innovation of exchange transfusion, also called therapeutic plasma exchange, enabled pediatricians to treat babies born with conditions such as anemia caused by hemolytic disease.[8] Third, the development of anti-D immunoprophylaxis in New York and Liverpool in the mid-

[7]Unpublished paper, "Haemolytic Disease," 1973, Postgraduate School of Obstetrics and Gynecology, University of Auckland.

[8]See Koenig (1988) for an excellent historical anthropological account of the development of therapeutic plasma exchange.

1960s, and its widespread use internationally after 1968, drastically reduced the number of pregnancies affected by Rh disease. This "vaccine" is given to Rh-negative women after their first pregnancies. The drug effectively inhibits antibody production by "lending" women antibodies which destroy the antigens, thus preventing women from developing permanent immunities to antigens that may be present in subsequent pregnancies.

While all of these efforts focused ultimately on fetal and infant health, actual treatment was accomplished either by treating the pregnant woman or treating infants after birth. None of these medical advances were as critical to the emergence of the fetal patient as intrauterine transfusion, or transfusion of fetuses at risk for hemolytic disease while still in the womb. Pioneered by Liley and his colleagues, intrauterine transfusion captured both the popular and clinical imaginations by breaching a hitherto uncrossed therapeutic boundary. As news of Liley's achievements spread across the globe in 1963, the "unborn patient" became a new social and clinical entity. The story of intrauterine transfusion, and the medical work through which the fetal patient was crafted historically, begins then in New Zealand.

Finding the Fetal Patient in Aotearoa, "the Land of the Long White Cloud"

It is difficult to visit the islands of New Zealand and not feel an almost primal connection to the landscape defining these small volcanic jewels in the South Pacific. The Maori who settled New Zealand's northern island long before the *pakeha*, or Europeans, had a word for their beautiful and lush homeland surrounded by blue-green sea: *whenua*. This same word also refers to the placenta, the membrane between a pregnant woman and her fetus which nurtures the growing fetus. Given the rich and evocative meanings of *whenua*, it seems fitting somehow that fetal surgery, an important chapter in the history of reproductive medicine, began in New Zealand. Those whose work facilitated the construction of the fetal patient, such as Liley and

his colleagues, shared with the Maori a deep and abiding connection to their homeland. Yet as much as they were men of the earth, engaged in forestry and farming, they were also men of medicine and science, skilled in the most up-to-date medical techniques and well-versed in current clinical knowledge.[9] It is the unique fusion of medical and scientific work with circumstance, time, and place which culminated in the social debut of the unborn patient.

The Significance of Place in the History of Fetal Surgery

Albert William Liley, called "Bill" by almost everyone who knew him, was born in 1929 into a working-class family in Auckland.[10] As a child, he was fascinated by New Zealand's landscape, joining the Auckland Botanical Society and planting a native forest in his family's backyard. Drawn to the "natural" world, he likely could have pursued either forestry or science. His family physician suggested a career in medicine, and Liley responded with enthusiasm. After placing first in New Zealand's national scholarship competition in 1947, he began college at Auckland University the following year. He studied medicine at university, and then went on to New Zealand's only medical school at that time, the University of Otago in Dunedin. After graduating from medical school in 1954 with degrees in both medicine and surgery, he became interested in a scientific career and was recruited by Nobelist John Eccles at

---

[9]"Every Saturday morning after ward rounds and surgery at National Women's Hospital, they leave behind their white coats, scalpels, and stethoscopes and grab axes and slashers to become weekend forestry rangers. To the nurses, medical students and young house surgeons who probably stand in awe of them these three men are Professors Sir William Liley, G.C. Liggins, and G.H. Green, eminent gynecologists all. But to the farmers, bushmen and contractors around Kaukapakapa they are plain Bill, Mont, and Herb. Ten years ago this medico partnership...bought 450 acres of former farmland that had reverted to fern, gorse and scrub. Today the rugged tract of hilly country is a thriving pine forest--and all the handiwork of men more used to dealing with the human fetus than with pinus radiata seedlings" (Macdonald 1973). One contemporary fetal surgeon told me, with obvious admiration, of meeting Liley for the first time and noticing how "rugged" his hands were: "They were definitely the hands of someone who worked outside, and not really the hands of a surgeon." McCarthy (1983:5) recounted that "[Liley's] weekend pursuits led to one patient complaining that she felt gorse prickles in his hands when he examined her."

[10]In addition to interviews with his family and colleagues and review of his papers, information on Liley was obtained from Anonymous (1972), Shadbolt (1976), and Green (1986).

Australian National University in Canberra. There he studied neurophysiology and received a Ph.D. in 1956.

At this point in Liley's career, a sense of place interceded in consequential ways. Although fascinated by the intellectual demands of neurophysiology, Liley felt that scientific research was too esoteric. He wanted to work with people and, more importantly, he wanted to work in New Zealand. He felt that to have a successful career as a research scientist would mean not returning home, and this he could not abide by. He had married a fellow medical student, Margaret Hunt, shortly after graduating, and they had purchased some rugged land in the center of the north island near Taumarunui, in what is known as the hill country. Liley felt a strong, almost primal connection to New Zealand, and after returning spent much of his spare time working on forestry and farming.[11] He once described his love for his home as such: "My attitude to New Zealand is that of the poet who, when asked in England why he was returning to New Zealand, said that much of the time he enjoyed being a poet and all of the time he enjoyed being a New Zealander."[12]

Although well-trained as a research scientist, Liley needed hands-on clinical training for a career in medicine. Shortly after returning to New Zealand, he began a research fellowship in obstetrics at the Postgraduate School of Obstetrics and Gynecology, University of Auckland. The Postgraduate School was established in 1951 by a group of women working with the Obstetrical Society who felt that New Zealand should have its own training ground for obstetrics and gynecology, rather than

---

[11]Florence Fraser remarked to me, "Bill had an amazing general knowledge and could talk about anything, like building bridges. You were down in Taumarunui, weren't you? We were always getting bulletins on the forest or the bridge." Over time, the Lileys' 1,200 acres of rough land has been transformed into a picturesque and impressive farm with Norfolk pines and a lively assortment of animals including sheep, cattle, dogs, and cats. Liley's widow, Margaret, runs the farm in partnership with her son, Bill, Jr., a forestry consultant.

[12]Quoted in Anonymous (1972). Liley also stated that, "I might get ten times as much money if I worked overseas. In many places I'd need just about that amount to make life tolerable...In the U.S. I like nearly all the Americans I've met in 31 states. Trouble is, I find that at times I haven't got a good word to say about their country. Do you know that if there were no cars in Manhattan there would be 65 extra days of sunshine each year. Hell, if I'd been brought up in a high-density housing area in that country I'm damn sure I'd have been a juvenile delinquent" (quoted in Reid 1973).

continuing to send physicians to England and elsewhere.[13] Spearheaded by Dr. Doris Gordon,[14] the campaign began in the early 1940s with fundraising and advocacy efforts. As Gordon wrote to a colleague, "Even though it looks as if war is in New Zealand waters it still requires the old methods of public clamour to generate courage to spend among our politicians." After obtaining the requisite funding and discussing a variety of possible sites, the Postgraduate School was eventually located in what had been, during WWII, the 39th General Hospital of the U.S. Army (Green 1986). Situated in a wide green park at the base of an extinct volcano, the Postgraduate School became the hub of obstetrical research and training in New Zealand.

Dr. Harvey Carey, an Australian, was appointed Director in 1954 and began transforming the School into a solid research center. He recruited Liley, fresh from his doctoral training in Canberra, in 1957 and appointed him as the School's first permanent research fellow. It is here where Liley, working in collaboration with Carey, Graham Liggins, and others, developed the technique of intrauterine transfusion, performing his first transfusions in an annex to the U.S. Army recreation hall (Green 1986). According to Ross Howie, who began as a pediatric resident in 1962, the Postgraduate School was "a good place to work." There was "good leadership by Carey," and the department was not beholden to the "publish or perish mode" of most academic settings. Rather, research was cooperative and friendly, with little competitiveness. As Howie also pointed out, experimental animals were always available: at that time there were 60 million sheep in New Zealand (as compared to

---

[13]Dr. G.H. Green has prepared an unpublished overview, "The Founding of the Postgraduate School of Obstetrics and Gynecology" (1976), from which much of this material is drawn.

[14]In 1956, Sir Bernard Dawson, Professor Emeritus of Obstetrics, University of Otago, wrote an obituary of Doris Gordon in the *Otago Daily Times*, stating, "It is safe to say that no one has contributed more to British obstetrics and to the welfare of the women of New Zealand. Dr. Gordon's achievements and long record of voluntary effort were in 1954 recognized in Great Britain when they were rewarded by the Honorary Fellowship of the Royal College of Obstetricians and Gynaecologists. This, the highest distinction of the College, has been bestowed on only twenty of the leading obstetricians of the world. Dr. Gordon is, apart from the Ladies of the Royal Family, the only woman to be so honored, and is the only Honorary Fellow in the Southern Hemisphere. Her death is a sad loss to New Zealand, the end of a life of ceaseless efforts for the good of the Dominion, which deserve the fullest recognition."

3.5 million people).[15] This, combined with talented people of "ability and ideas," made for "an exciting research climate."

The Postgraduate School was developed in conjunction with National Women's Hospital, within which it was and still is located. The hospital was set up under an act of Parliament to provide every woman in New Zealand with free access to health care. Originally established as a site for research and teaching, the Postgraduate School moved to its current location with National Women's Hospital in 1964. The hospital is located near the base of One Tree Hill, the site of a Maori *pa*, or fortified village, with breathtaking vistas of the Auckland region. It is part of the campus of Greenlane Hospital, at the end of Claude Road in a residential neighborhood of lovely frame houses with neat gardens. The building itself in which the school is located represents 1960s functional architecture at its zenith, although the small birds flying in and out of the open-air cafeteria add a touch of whimsy to the otherwise austere setting.

As a national medical center, National Women's has, since its inception, provided health care services for women from all over New Zealand, as well as from nearby areas of the South Pacific. Thus, the patient population historically has been, and continues to be, highly diverse, including European, Polynesian, Melanesian, and Maori women.[16] In the 1960s and 1970s, after news of Liley's achievements with intrauterine transfusion spread, women often came from as far away as the U.S., Spain, Sri Lanka, and India for medical management of their pregnancies. In 1967, for example, an Indian physician wrote to Liley asking if she could travel to Auckland so

---

[15]Experimental research in sheep was fundamental to the development of fetal physiological knowledge and fetal treatments. During the 1960s, both Liley and Liggins spent a great deal of time at Ruakura, an agricultural research station located near Hamilton, the major center for dairy, farming, and research in the North Island. I discuss sheep research in greater detail in Chapter 4.

[16]However, all of these groups are not equally represented among Rh patients. Howie told me that approximately 14% of women of European descent are Rh-negative. Hemolytic disease was virtually non-existent in Polynesian, Melanesian, and Maori populations until migration resulted in ethnic mixing. Approximately 8% of women in Northern India are Rh-negative, and the highest Rh-negative rate is in Basque and Latin populations.

that he could monitor her pregnancy. She wanted to be taken on as a staff member and thus have her medical costs waived. Liley wrote that "in view of the world drop in wool prices, work permits for people overseas are in fact very hard to get in New Zealand at the moment." It is not clear from the letters whether this physician ever came to Auckland or not. Another 1967 letter, this one from a colleague in Fiji, concerned a woman whose fetus required a transfusion. The referring physician stated that in light of the Fijian government's "family reduction efforts," it would likely be "unwilling to pay for a trip to New Zealand." This letter, and others like it, illustrate how health care for Polynesian women from neighboring countries was often shaped by political and economic factors.

These examples drawn from Liley's voluminous correspondence illustrate the dynamic, diverse nature of his work and the central role of the Postgraduate School and National Women's Hospital in obstetrics research during that era. Liley's research on hemolytic disease, the development of intrauterine transfusion, and the establishment of a prophylaxis scheme for treating Rh disease all occurred within a context shaped by history and geography. Yet as the Rh work was unfolding, another chapter in the making of the unborn patient was being written. While Liley's work emphasized direct, intrauterine treatment of fetuses using needles to transverse the womb, other work at National Women's Hospital focused on non-surgical aspects of fetal treatment and provided a foundation for the surgical approach. As Liggins pointed out, "In National Women's Hospital, both surgical *and* medical intervention began." Both forms of treatment have had far-reaching consequences for fetal medicine. Before moving on to the story of intrauterine transfusion, I first discuss the non-surgical approach and its role in the making of the unborn patient.

Non-Surgical Fetal Treatment: Corticosteroids and the Unborn Patient

As intrauterine transfusion technology was making international headlines, Graham Liggins and Ross Howie were quietly demonstrating that fetal treatment was not limited to the "invasive" approach. Building on animal experiments, they administered corticosteroids to facilitate lung growth in fetuses and premature babies, a technique still in wide use. Considering the context in which corticosteroid research unfolded, its concurrent development with surgical advances in fetal treatment is not at all surprising. Liley's work with fetal transfusions depended to some degree on a solid understanding of principles of fetal physiology, which Liggins had spent years researching in animals and attempting to elucidate.[17] Liggins remembers, "Bill and I worked very closely together. I did a lot of fetal transfusions, and Bill was away for a year [in 1964] and I looked after the whole thing...We were also really close friends, shared not only our work interests but also our extramural interests...There was certainly a cross-fertilization." Liggins was interested in technical aspects of fetal transfusions and developed impaling techniques to access fetuses for diagnosis and treatment.[18] Also, patients admitted to National Women's Hospital for Rh care by Liley's team were often delivered prematurely to avoid hydrops, thus providing Liggins and Howie with a steady supply of research subjects.[19] In short, National Women's

---

[17]See Gluckman, Johnston et al. (1989). The significance of animal research, particularly in sheep, to the development of these practices cannot be overestimated. Liggins told me, "I guess we were the first people who were able to carry out what's called chronic fetal experiments. That is, do things to a fetus and have the pregnancy continue in experimental animals. Our ability to carry out these procedures was the basis for our discovery of the mechanisms of onset of labor in sheep."

[18]Prior to the development of ultrasound, impaling techniques were used to locate and steady fetuses during diagnosis and to treat them using catheters. Liggins (1969:516) described this work: "A flock of 43 pure-bred Romney ewes was used...A self-retaining catheter was inserted into the fetal peritoneal cavity...and corticosteroids dissolved in 0.9% NaCl solution were infused continuously."

[19]Hydrops is an excessive accumulation of fluid in any of the tissues or cavities of the body. In the fetus, hydrops refers to the abnormal accumulation of serous fluid in fetal tissues and signifies the terminal phase of hemolytic disease. Radiologic analysis was historically used to identify hydropic fetuses: "The remaining classic signs of erythroblastosis are well known, comprising deflexion of the fetal trunk and head, displacement of limbs from the trunk, flaring of the lower thoracic cage, scapular displacement exceeding 1 cm. from the ribs and faintness and widening of the fetal subcutaneous fat shadow" (Liley 1968:33).

Hospital provided a fertile setting for the development and emergence of both non-surgical and surgical fetal treatment practices.

In one sense, however, serendipity played a role in the development of non-surgical corticosteroid treatment. Liggins had long been interested in the physiological mechanisms responsible for the onset of labor, conducting most of his research in sheep.[20] In a series of animal experiments he claimed to demonstrate that it was the fetus, not the mother, that controlled the time of onset of labor (Dawes 1989). During the course of that work, he discovered that by destroying the fetal pituitary gland, parturition was avoided and the fetus continued to grow. He recalled, "What I'd done was remove the pituitary in the fetal sheep, and allow the pregnancy to continue without the gland, and the pregnancy would go on forever. Conversely, if you infuse into the fetus the hormone ACTH, which is a pituitary hormone that drives the adrenal, or cortisol, which is an adrenal hormone in the placenta, the animals deliver prematurely. And the lungs of the babies, even though they died quickly, had retained air...So we were noting this effect and I realized that the cortisol or the ACTH was accelerating the development of the fetal lungs. Ross Howie and I then pursued this in lambs about to deliver prematurely."

Following a trial in which 43 sheep were given cortisol and other hormones (Liggins 1969), Liggins and Howie (1972:524) conducted their first clinical trial in humans. They found, as Liggins told me, that "the hormone cortisol, regardless of species, prepares the fetus for birth." Liggins and Howie had established that corticosteroids administered prenatally stimulate lung development in the fetus. This

---

[20]Liggins, although formally trained as an obstetrician, was deeply interested in the intricacies of fetal physiology. Trained in New Zealand, he spent a fruitful sabbatical at the University of California, Davis, in 1966 where he investigated fetal physiology, specifically the fetus' role in onset of labor, in sheep. Geoffrey Dawes (1989:1), considered one of the premier twentieth-century fetal physiologists, wrote about that period in a *festschrift* in Liggins' honor: "I first met, talked of fetal physiology, and fished with Mont Liggins in California in 1966, where we were both on sabbatical leave, he in Davis and I in San Francisco...In retrospect it was the start of a remarkable epoch in which, over 2-3 years, experimental perinatal physiology and medicine were given a new direction through Mont Liggins' elegant and deceptively simple results." In 1970, Liggins spent three months at Oxford with Dawes, where he developed chronic fetal sheep preparations for research on fetal breathing and lung volume.

finding had significant clinical implications for premature babies born with immature lungs who subsequently develop respiratory distress syndrome. Corticosteroids promised to ameliorate this problem in prematurity, resulting in healthier babies and higher survival rates. From such experimental work in the late 1960s and early 1970s, corticosteroid treatment has since become a routine practice in obstetrics. Liggins remarked, "Our test results have stood the test of time, and this has become standard treatment throughout the world...Probably hundreds of thousands of babies have survived who might not have survived."

Yet moving from experimental research in sheep to standard care in humans required some modifications in the procedure. With sheep, fetuses were infused directly with cortisol using self-retaining catheters. In humans, however, the placenta is much more permeable, making maternal administration of hormones "a feasible means of subjecting the human fetus to high levels of glucocorticoid activity" (Liggins and Howie 1972:516). Once it was established that cortisol could cross the placenta and enter the fetus' bloodstream, treatment became fairly simple. Hence the trajectory of corticosteroid treatment was quite different from that of fetal transfusions, primarily because it was an easier technology to use. National Women's Hospital became a center for Rh treatment because it was a difficult procedure and other institutions were not yet prepared to do it. This was not the case with corticosteroid treatment. Liggins stated, "Women didn't have to travel to Auckland. It was such a simple treatment anybody could do it. What happened initially is a number of centers set up similar controlled trials, and within quite a short time, say three or four years, a half dozen or more comparative studies were done." Thus, non-surgical fetal treatment was able to be exported to other medical centers to a degree that fetal transfusion was not.

It is ironic that fetal transfusions, which saved at most thirty babies per year in New Zealand, captured the world's imagination, while corticosteroid treatment, which

has become standard care and has saved many more babies, did not. Both forms of treatment were based on the same body of experimental research, used many of the same techniques, were performed by many of the same practitioners on some of the same patients, and occurred within a single institution, National Women's Hospital. What this distinction in public reception and the weight of the historical record indicates is that although there is tremendous clinical interest in all aspects of fetal treatment, it is breaching the womb which both fascinates and compels a wider audience. Administering a hormone to a pregnant woman which then is passed to her fetus through the placenta seems not nearly as exciting as the drama of penetrating the uterus and its contents with needles, catheters, and surgical instruments, fully *intervening* in pregnancy itself. It is fitting, then, to turn our attention to the surgical approach to fetal treatment and the development of intrauterine transfusion technology.

"Peacekeeping on the Maternofetal Frontier": Serendipity and Medical Work in the Development of Intrauterine Transfusion[21]

Liley may well be considered the "father" of fetology for his role in developing the technique of intrauterine transfusion, but there were a number of other actors involved in this enterprise as well. As discussed above, the working environment of the Postgraduate School was cooperative and characterized by a range of activities organized around preventing and eradicating hemolytic disease. Liley practiced closely with other members of the Rh team, including G.H. Green, the head of the department and an active clinical researcher; Liggins, an obstetrician with expertise in fetal physiology; Florence Fraser, also an obstetrician and Liley's tandem colleague on the Rh team; Sally Kinnock, a researcher and the Rh Committee secretary; Ross

---

[21] Liley described Rh work as such in a 1980 presentation in Long Beach, CA, entitled "Rh Hemolytic Disease: Peacekeeing on the Maternofetal Frontier."

Howie, a pediatrician; Neal Patterson, an obstetrician; and many additional practitioners representing pediatrics, obstetrics, radiology, blood banking, and other specialties. The Rh research project undertaken at National Women's Hospital in the early 1960s thus mobilized a diverse group of medical workers who brought to their task different skills, interests, and commitments.

A significant illustration of this was the development of the Rh Committee, which represented a microcosm of the social organization of fetal treatment at that time. In one important sense, cooperation was necessitated by the clinical demands of maternal antenatal care for hemolytic disease. Pregnant women who came to National Women's Hospital for evaluation and treatment were often seen by several different specialists, ranging from obstetricians caring for the women to pediatricians who would treat surviving newborns upon birth. The Rh Committee was set up to provide some cohesion to this heterogeneous group of practitioners, and to add a degree of organization and coordination to patients' trajectories through the health care system. According to Florence Fraser, "The Rh Committee started because we had a specialized team here for managing hemolytic disease. The Committee consisted of pediatricians, obstetricians, plus the Rhesus team, and the blood bank.[22] So the decisions, even in dire emergencies, were made with consultation if there was

---

[22]The importance of the blood bank to the organization of Rh treatment cannot be overestimated, as fresh blood was absolutely necessary for both fetal and neonatal transfusions. Liley maintained continuous correspondence with staff of the Auckland Blood Bank, as well as with blood banking personnel within National Women's Hospital. A significant portion of his records include correspondence and internal memos about blood banking procedures, including questions about necessary volumes, blood types, availability, transport, and transfusion techniques. In a 1977 letter to the retiring director of the Blood Bank, J.M. Staveley, Liley wrote: "We have always been aware how much our standards of clinical care in many problems have been determined by the service available to us from Blood Bank, how much your own directorship has contributed to the service and the reassurance which the ready availability of your advice and opinion has been to us on many occasions. As one who has seen a large number of blood banks in many places in the world, personally I am vicariously very proud of our one here and of its outstanding safety record. We have particularly appreciated your interest in our Rh problems and your continued attendance at our Rh Committee Meetings, an attendance which I might add is much more regular than that of our senior consultants."

time...And I think this led to a safer and better outcome. Because forewarned you're forearmed."[23]

It is within this particular medical setting that Liley pursued his research interests in Rh disease, beginning with prenatal diagnosis (Liley 1960, 1961, 1963, 1965a). After returning from Australia and joining the faculty of the Postgraduate School, Liley eagerly set about selecting an area of clinical research. His colleague Liggins remembers Liley wanting an area "that was both important and about which something might be done. So he identified hemolytic disease as fitting those criteria, and set about systematically to do something about it. And clearly the first step was to go and make a diagnosis of hemolytic disease and its severity." Liley was fascinated by amniotic fluid, in part because "it belongs primarily to the fetus. It is the only part of the conceptus which can be sampled reliably with relative impunity and, if necessary, repeatedly. Tests on the amniotic fluid are tests on the fetus and his environment" (Liley 1972a:199). Amniocentesis was a key factor in early constructions of the fetus as a distinct work object and patient.

Drawing on the prior efforts of Bevis (1952; 1956), Liley applied the technique of amniocentesis, or spectrophotometric analysis of amniotic liquor, to Rh-impaired fetuses. Liley would insert a sharp, 3.5 inch, gauge 20 lumbar puncture needle through a pregnant woman's abdomen and into the amniotic sac. Locating the sac without harming the fetus in this pre-ultrasound era was both challenging and risky.[24]

---

[23]Fraser also stated, "I think because we involved anyone that might be interested, a team of people, we didn't have any major ethical problems." The contemporary incarnation of the Rh Committee at National Women's Hospital is the Fetal Medicine Advisory Panel, chaired by Liggins. This is a city-wide service group comprised of physicians, laboratory workers, surgeons, pathologists, and others who review cases and determine fetal treatment policy.

[24]Amniocentesis as used by Liley illustrates some of the material aspects of accessing maternal and fetal work objects: "The fetal position was checked and a likely spot for puncture selected. With lateral or posterior positions this was usually a site where fetal limbs were readily palpable...The site having been selected, local anesthetic was injected through the parietal peritoneum...Translation of the needle showed that the tip was still in the abdominal wall while angulation indicated that the tip lay somewhere in the uterus. Violent or erratic angulation suggested fetal puncture or, more commonly, that the tip lay among fetal limbs...With a rather blunt needle two distinct 'gives' were felt as the anterior and posterior rectus sheaths were penetrated. A further 'give' was felt as the needle entered the amniotic sac or intervillous space. With a very sharp needle these landmarks were often imperceptible but the puncture could be more

Analysis of the amniotic fluid indicated the level of anemia in these fetuses, allowing an assessment of "the condition and prognosis of the individual baby" (Liley 1963:238). Used in this way, the technique enabled physicians to decide in which pregnancies to induce labor to prevent stillbirths and to avoid severely anemic neonates.[25] Thus, early "treatment" efforts focused on ascertaining when to leave low-risk babies in utero and when to deliver others prematurely with minimum risk. As Liley (1963:240) put it, "the practical implications of these observations is that if all Rhesus-sensitized women are subjected to amniocentesis some time between 29 and 32 weeks, a group may be defined in whom the fetal condition is already critical, with very premature delivery a matter of urgency and...desperation." After incorporating amniocentesis into the Rh work at National Women's Hospital, "the erythroblastosis perinatal mortality was reduced from the 22-25% prevailing before 1958 to less than 9% by 1962" (Liley 1965d:837).

Yet there was one group of fetuses for which early prenatal diagnosis and selective induction were insufficient. Liley (1965d:837) identified these fetuses as being the "third grade of severity, with very large pigment peaks portending fetal death or hydrops before 34 weeks gestation. For such patients conventional treatment has little to offer since gross immaturity and severe anemia or hydrops makes very premature induction a desperate and disappointing exercise."[26] The possibility of using amniocentesis to identify at-risk fetuses prompted Liley to consider additional aspects of treatment beyond conventional therapy. As Liley (1971b:303) wrote, "It was very frustrating to have to put a diagnosis on a baby which was virtually a sentence of death and then sit back and watch the baby die." About

---

gentle and controlled. By the same token, however, puncture of...the fetal thigh could meet very little resistance and indeed very little protest from the fetus" (Liley 1960:581-2).

[25]Liley and his colleagues felt that clinical signs such as radiological evidence of hydrops were insufficient, and the opportunity to help the fetus in a timely fashion would almost certainly be lost. "Only a specific test on the current fetus can provide the necessary indication and only amniocentesis fulfills this role" (Liley 1965c:70).

[26]Op. cit. note 19 for a definition of hydrops.

this time, two serendipitous events occurred which dramatically affected the course of fetal therapy and promised to alleviate Liley's frustrations.

First, during a routine amniocentesis, Liley accidentally punctured the distended fetal abdomen, with interesting consequences: "Instead of getting deep yellow, cloudy amniotic fluid, I got brilliant, golden, clear fluid which was obviously ascitic fluid; this windfall was easily confirmed by injection of contrast medium. Now this had not been intended, and initially it was rather disconcerting, but it did not appear to disturb the fetus--who was a write-off anyway. However, it occurred to me that if we could needle the fetal peritoneum without even trying then perhaps we could do it deliberately and put it to some good use" (Liley 1971b:303). Liley considered the possibility of using this route for transfusion, yet wondered if the fetus would absorb blood cells rapidly enough to offset anemia. Liggins had also recently accidentally invaded the peritoneal cavity in a pregnancy where there was no amniotic fluid. In this case Liggins was injecting contrast medium before doing an amniogram; when the medium missed its mark, the amniotic fluid, it instead "gave a lovely picture of the fetal peritoneal cavity." As Liley and Liggins were about to embark on a research project to determine the feasibility of peritoneal transfusion in treating fetuses, fate and a sense of place intervened yet again in this line of work.

The second serendipitous event concerns the role of an English geneticist whose name has long since been forgotten (Liley 1971b; Green 1985). This young doctor stopped in Auckland on her way home from Nigeria, where she had been working on sickle cell disease in African children. "With her she had some beautiful blood slides from neonates and infants, homozygous for HbS, who had been given normal cells intraperitoneally. There were floods of normal cells in their peripheral blood, and this was good enough evidence for us that cells could be taken up from the peritoneum in massive quantity and at a relatively rapid rate. We therefore went directly to the fetus" (Liley 1971b:303). The English doctor's contribution to the

development of intrauterine transfusions cannot be overestimated, even if her name is no longer part of the historical record.[27] As Liggins put it, "When the English lady came along, of course, Bill got the idea of putting blood into the peritoneal cavity."

The idea behind fetal transfusion for Rh disease, according to its practitioners, was to "tide over to a more viable maturity the baby severely affected by hemolytic disease in the second or early third trimester" (Liley 1965c:70). In other words, transfusions could be performed in fetuses too young to survive premature delivery but which would likely die in utero if left untreated. It is important to emphasize that despite the severity of hemolytic disease, the scope of fetal transfusion for Rh-affected fetuses was quite limited. Of the approximately one in 200 pregnancies complicated by Rh sensitization, about 90% could be managed by more conventional methods. At most, "only one in 2,000 pregnancies may require transfusion of the fetus to help protect it from intrauterine death or gross prematurity. Thus, for the whole of New Zealand the procedure need be carried out only about 30 times in a year" (Green, Liley et al. 1964). For this small number of fetuses, transfusions were seen as life-saving. Yet the temptation to use the technique for fetuses at lesser risk was compelling. Liley (1965d:842) wrote, "if the procedure can benefit babies at 100% risk, it should also benefit babies at only 50 or 30% risk." Yet he also preached caution, stating that "what is necessary is more important than what is possible, and extreme measures are best reserved for extreme situations...there is little justification for exposing the fetus and mother gratuitously to the risk of unnecessary transfusions when a much less complete restoration will suffice" (1965:841-2). Possible maternal risks included "increased maternal sensitization by placento-maternal leak, hemolytic reaction from

---

[27]Although the 22-year old geneticist's name has been lost, every person I interviewed about the historical aspects of fetal surgery presented in this chapter told me this story of serendipity and a chance encounter. David Becroft, a pathologist at National Women's Hospital, attempted to identify this woman but had little luck. He thought he had located her at one point, but the woman he identified turned out to be the wrong one. Who was this mystery woman?

massive feto-maternal transfusion, accidental hemorrhage, hemoperitoneum, and infection" (Liley 1964:148).

Liley's first successful transfusion in September 1963 was performed on a 32-week male fetus, followed by a second transfusion 10 days later and an induced delivery at just under 35 weeks. It was the fourth pregnancy for the maternal patient, Mrs. E. McLeod; her first had been successful, the second ended with intrauterine death, and the third with stillborn twins. This baby, Grant Liley McLeod, was severely affected by hemolytic disease and would likely have died within a week of diagnosis had treatment not been performed. Yet prior to this landmark procedure, Liley had attempted three unsuccessful transfusions in fetuses which died. The first two failed for technical reasons: "Both babies died--as hydropic babies tend to do--in a day or so; it appeared that if we were to be successful we would have to get in before we had such a big target and before we had any fluid to tell us where we were...You will note that our use of epidural needles and catheters for this task was not fortuitous" (Liley 1971b:303-4). The third transfusion, although unsuccessful, was instructive: "Our last failure rather than our first success was what convinced me that we were on the right track, as the fetus lived on long after it should have died. Our problem was that, ignorant of the magnitude of the feto-placental blood volume, we undertransfused it at the initial transfusion and then had no idea when to repeat the performance. With the next baby we began to remedy these problems" (Liley 1971:304). Having weathered this process of trial and error, Liley realized that not only were multiple transfusions necessary to treat fetuses in utero, but that some babies would likely need to be transfused again after birth.

Like most new medical procedures, intrauterine transfusions were challenging, particularly in the initial period before the technical wrinkles were ironed out in

practice.[28] Also, much of this work took place prior to the development of ultrasound, which has made assessment of fetal position quite simple to determine. What follows is Liley's (1965b:929-30) description of fetal transfusion, illustrating both the technical aspects of this medical procedure and constructions of the fetus as a work object:

> Under local anesthesia and maternal premedication the fetal peritoneum is punctured with an 18 cm G 16 Touhy needle. The first guide to position is a distinct yield as the dimpled fetal abdominal wall is punctured. A syringe of sterile saline is used to check that free injection but no aspiration is possible. A nylon epidural catheter 50 cm long is fed up to the hub of the needle and the needle withdrawn. The catheter position is checked by injection of 3-6 ml of contrast medium which reveals the characteristic shadows of intraperitoneal dye. Fresh citrated, group O, Rh-negative blood, crossmatched against mother's serum, packed to a hemoglobin of 18 to 23 g% and warmed, is slowly injected. Quantities from 85 ml at 27 weeks to 150 ml at 32 weeks appear well tolerated. Antibiotic cover is provided.

One of the most frustrating aspects of this practice was actually finding and penetrating the fetus with the needle. Both amniograms and hands-on examinations were used to ascertain fetal position; often, pregnant women were shifted around to provide physicians with better access to fetuses. The consequences of missing the peritoneal cavity could be quite severe, including puncturing of other fetal body parts or

---

[28]In the first year during which fetal transfusions were performed at National Women's Hospital, there were 16 cases involving 22 fetal transfusions. The success rate was not very high: six surviving fetuses or a survival rate of 37.5% (Green, Liley et al. 1964). In 1969 the survival rate had risen slightly to 39.5%, based on 167 pregnancies, 328 fetal transfusions, and 60 survivors (Liley 1969). Fraser told me that when she started on the Rh team in 1973 the survival rate was about 45%, and when she finished it had risen to 60-70%.

rupture of the amniotic sac. Florence Fraser described the challenges of this work: "If the fetus wasn't in a good position, we would put a second needle in, then a third or fourth. There were very few patients where we gave up...Usually the very little ones were the very difficult ones. Sometimes between 18 and 22 weeks you can't hit your target. Like trying to catch a golf ball in a bucket of water."[29] According to Liggins (1966a:617), "as the fetus explores the roomy confines of the amnion in its efforts to evade the intruding needle, it becomes a very elusive target." The difficulty in accessing fetuses, particularly very small fetuses from 23-27 weeks, resulted in two important modifications of the initial transfusion technique.

The first technical modification was the introduction of two needles, one a fine guide-needle upon which the fetus was impaled to hold it in place and the other a catheter for transfusion.[30] Fraser made use of this technique in practice: "If they were very young, the first needle we put in would be a very long, fine needle, and the aim would be not to hit the right spot necessarily. We'd aim for it, but we'd hold Fred still while we put the bigger needle in."[31] The second technical modification was the development of a self-retaining catheter to make transfusions more efficacious. As Liggins (1966b:323) points out, "the need for rapid transfusion arises from the observed ability of the fetus to expel as much as 50 cm. of catheter from its peritoneal cavity within a short period. Inevitably, as the volume transfused approaches the limits of tolerance, some less robust fetuses will succumb." The self-retaining catheter allowed for selecting the optimal rate of transfusion, which "could extend the

---

[29]Yet the physicians often developed relationships with their concealed, evasive fetal work objects that extended even beyond birth. Fraser told me, "I would talk to them while I was working on them. Now look fetus, give me your tummy...There was one baby I did three or four transfusions on, and he went home...I missed him, and his mother brought him up to see me..I spoke to him and called him by name...and he opened his mouth and bellowed. As if he associated my voice with unpleasant things."

[30]Liggins (1966a:618, 621) stated, "The idea of blindly impaling the fetus on a skewer as a guide to the insertion of the catheter introducer is rather repugnant. Experience has shown however that this simple procedure facilitates successful entry of the fetal peritoneal cavity by a much wider cannula and largely eliminates the trauma to fetus and mother from its repeated insertion...The impaling technic offers a real prospect of salvaging the fetus otherwise destined to be hydropic by Week 25-26 of pregnancy."

[31]Throughout my interview with her, Fraser referred to fetuses as "Fred," which is what she used to call them in practice.

scope and safety of peritoneal transfusion, particularly in the less mature fetus prior to the thirtieth week" (Liggins 1966:323). As with the impaling technique, the self-retaining catheter was designed to enhance access to the fetal patient as a work object during transfusions.

The nature of this work was not simply technical, however. It was also highly social and involved a great deal of interaction with patients and their families. Because the pregnant women came from all over New Zealand, as well as from other countries, their care often required additional support beyond clinical care. Liley, Fraser, and others who worked on the Rh team often developed close, long-term relationships with their patients.[32] Fraser remarked, "I used to spend a terrific amount of time with the mothers...We tried to keep their lives as normal as possible, as much as you can in a hospital. If they wanted to talk, both of us would make time to just sit down and talk to them, and I think that's why Bill and I both ended up with a lot of friends. You know, I still at Christmas time get fantastic little bulletins about patients." An important component of this work was providing psychosocial support for the pregnant women. Fraser described this aspect: "Your social and psychological support are terribly important, because you've got to have a peaceful calm...We did a lot of social working on the job, and to me that was part of the job. And Bill felt the same way...For both of us, our day here started with a trip to the wards to see all the patients...I couldn't start the day without knowing they were all okay and happy, and that junior was happy."[33]

---

[32]Although it is impossible to ascertain how Liley interacted with his patients, his concern for them is evident in both his published articles and correspondence with and about individual patients. Liley carefully responded to letters from women all over the world who were seeking information about hemolytic disease and its treatment, sometimes writing back and forth for months. The tone of these letters is respectful, informative, and concerned, and they are very thorough in their explanations of the clinical issues.

[33]Concern about "junior" was a fundamental component of the Rh work. Fraser remarked, "I became very aware of the fetus as an individual early on...as far as I was concerned, fetuses do have personalities...I encouraged [the mothers] to think of their babies as personalities." Just as Liley had many babies named after him, Fraser told me that "there are a lot of Frasers and a few Florences out there."

In addition to working with patients, Liley and Fraser also had numerous interactions with colleagues from all over New Zealand who referred patients or wrote asking for information and treatment advice. These inquiries illustrate the degree to which National Women's Hospital was an epicenter of Rh diagnosis and treatment during the 1960s and 1970s. Correspondence between Liley and other physicians is testament to the ongoing consulting, disseminating, and negotiating work that comprised medical decisionmaking. For example, in one humorous letter Liley wrote, "In this situation it would have saved a lot of time and paper if he and I had sat down--preferably over a bottle of whiskey--and decided what to do ourselves. I appreciate that this might sound a little arrogant but by the time you have answered the same query from obstetricians in a dozen towns in New Zealand it gets a little boring." To a colleague in the South Island he wrote, "Mrs. P's story is interesting but by no means novel to us, at least in terms of development of antibodies after immunoprophylaxis in a previous pregnancy." And to a Fijian physician he wrote, "Your lady does not sound the most auspicious clinical prospect particularly as her husband is very likely to be homozygous. On the other hand if she is happy to attempt another pregnancy we will certainly be happy to try and help her. Even in the gloomiest group of customers where we are obliged to begin fetal transfusion at gestation less than 26 weeks we are still rescuing one baby in seven, and of course the further the baby can get under its own steam the much better its chances become."

Given the introduction of anti-D immunoprophylaxis, or the Rh "vaccine," for hemolytic disease in the 1970s, one might expect that fetal transfusions would have tapered off or that hemolytic disease would have been "conquered" (Zimmerman 1973). Yet Liley was all too aware that Rh disease was persistent and likely to remain a significant problem for at least some group of women. Fraser recalls Liley's response to anti-D: "Everyone here, when anti-D came, said of course this is going to end hemolytic disease, and Bill said, No it's not. He said it would cut out the mild

ones, but it would take an almighty blast to get the trigger happy ones, as he used to call them. There would still be a hard core of tough cases, and this is what it's turned out to be." Liley maintained an evolutionary perspective on the recalcitrant nature of hemolytic disease: "Clinically, there are three approaches to Rh problems. First, one could let women develop antibodies (or at least not prevent it) and then treat and save the babies--the pre-1968 situation. Second, we can aim to stop women developing antibodies in the first place--the immunoprophylaxis scheme. Third, a suitable dictator could decree that all three schemes have the same aim and effect--to hold the current gene frequencies constant--forever! Clearly this is somewhat a long term and ambitious campaign and in this context it is both naive and arrogant to speak of 'the conquest of hemolytic disease'."[34]

It is difficult to convey the excitement with which Liley's work was greeted in the 1960s. Intrauterine transfusion technology ushered in the era of the unborn patient, and the world responded with amazement. Some of the headlines describing this work in 1963 are indicative of the absolute novelty of treating fetuses still in the womb: "Transfusions Save Life in Fetal Anemia;" "How Unborn Baby was Transfused;" "Pre-Birth Transfusion Overcomes Rh Incompatibility;" "Transfusions of Blood Aid Unborn Babies;" "New Technique Means Life for Baby Girl;" "Blood Transfusion Before Birth;" and "Unborn Babe Given Transfusion." Zimmerman (1973:233) reported Liley's achievements in heroic terms, stating "Liley's needle had penetrated barriers beyond flesh and death on its way to the heart of the womb: breached, too, was the metaphysical barrier between the world of life that is and the universe of life that is yet to be. A fetus had been treated, medically, as one of us. Shattered, too, had been the barrier of medical custom. Prudence and caution had insisted until then that the womb and its contents were beyond the boundary of direct

[34]Quote taken from an unpublished paper in Liley's files titled "A Perspective of Rh Problems," (n.d.). The last sentence of the quote is almost surely a direct response to Zimmerman (1973). At the time of his death in 1983, Liley was working on research based on his statistics collected over several years which supported the notion that Rh disease was genetic.

medical intervention." Fetal treatment--breaching the womb--brought renown to Liley especially, but also to his colleagues, National Women's Hospital, Auckland, and New Zealand.[35] As one surgeon exalted about the first successful transfusion, "It is most rewarding and encouraging to find an Auckland medical case so extensively reported. For years New Zealand has been relying on gaining medical information elsewhere. This means the turning of the tide."[36]

Unsurprisingly, his accomplishments secured for Liley a place in the annals of medical history, as well as in the hearts of New Zealanders. Liley was perhaps the most well-known physician in New Zealand, particularly after being knighted by Queen Elizabeth in 1973 for his work in fetal treatment.[37] One of the offshoots of Liley's fame was the massive amount of correspondence he received from women asking for information about hemolytic disease. A sampling of these letters illustrates the degree to which news of Liley's fetal transfusion work spread across the globe, from Fiji to India to Spain to the U.S. For example, one woman from Savannah, Georgia, wrote: "I know you are a very important man so I won't take up much of your time. I got your name and address thru reader's digest...One year ago today they burried my baby. I carried my child nine months to the day. The week before she was born they ran an RH test on me. The Doctors said there wasn't enough RH Composits for it to be a blue baby...When they tried to transfuse my childs blood she

---

[35]Liley was, according to his colleagues, quite modest about his achievements. Liley himself once remarked to a colleague that "it is a cure for both arrogance and complacency to acknowledge that just because we are at the forefront of medical science we should not mistakenly assume we are at the pinnacle."

[36](Anonymous 1963).

[37]On one of my research trips to New Zealand, I was taking a ferry from Rangitoto, a volcanic island in Hauraki Gulf, back to Auckland after a day of hiking. On board I struck up a conversation with two middle-aged women who asked what I was doing in Auckland. No sooner had I uttered Liley's name when both women began nodding in recognition, saying things like "Of course, Sir Liley, what a wonderful man" and "Oh yes, Sir Liley, who did all that work on fetuses. His death was such a tragedy." I was both pleased and somewhat astonished that these two women knew who he was, but I soon learned that just about everyone I talked to in New Zealand knew of him. The elderly couple with whom I stayed in Hawkes Bay, a visiting couple from Wellington, the Belgian couple who ran a bed and breakfast in Auckland--all of them knew of Liley and his work. With very few exceptions, I could not think of any physician in the U.S. with such name recognition.

would destroy it before they could get a pint into her body. She lived twelve hours and then died...My little girl who is three is very lonesome and I would like to have more children. I am so afraid that I couldn't take the chance of losing another child...Do you think the reaction would show up again if I were to get Pregnant. Please help me with this."

Another woman, from Norfolk Island in the South Pacific, wrote: "Once again we are seeking advice from you...We look forward to your reply regarding J.H. as I know Dr. S. is also very anxious for her and flight bookings can be a great problem from here." Another set of letters from a man in Sri Lanka concerned his wife's pregnancy and related Rh problems. Spanning almost two years, these letters chronicle the pregnancy, birth, and death of the baby, and confronted the issue of whether the couple should travel to Auckland or to the U.S. or Britain for care in subsequent pregnancies. Liley responded that the decision to come to New Zealand versus the U.S. might be affected by the fact that "as you probably already know, medical care does tend to be disproportionately expensive in the United States in comparison with most places in the world." Liley's correspondence is filled with letters such as these, as well as copies of his detailed responses. If the volume and content of his correspondence is any indication, Liley's fame did not prevent him from treating each inquiry with care and respect.

In sum, medical work on hemolytic disease and the development of intrauterine transfusion technology in the 1960s sparked what one observer (Anonymous 1968) called a "quiet revolution" in the making of the unborn patient. By breaching the womb with needles and catheters and by directly treating fetuses surgically, Liley and his colleagues expanded the scope of reproductive medicine and redefined obstetrical care. Yet Liley's work was revolutionary in another sense, as well. Throughout his career, his professional and personal lives were closely intertwined around what he saw as the twin issues of fetal personhood and abortion. He was ardently opposed to the

practice of abortion and based his position on what he termed the "medical realities of achieving the pro-life ideal" (Liley 1979). Analyzing his participation in abortion politics as an activist and spokesman for the fetus provides a lens through which the imbrication of medical work focused on the fetal work object and reproductive politics may be clearly viewed.

"A Legacy of Life": Liley, Abortion Politics, and Fetal Personhood[38]

Liley was deeply interested in fetal life and devoted much of his career to describing and illuminating the world of the fetus with major linkages to and consequences for the international anti-abortion movement. A colleague once described him as "a giant among men who has dedicated his life to the tiniest human."[39] His clinical work, including fetal assessment and intrauterine transfusion technology, was an integral part of a broader fascination with and commitment to fetuses, or "unborn children" in his preferred terminology. While he labored to bring fetuses within the purview of modern medical practice as a new category of patient, he struggled simultaneously to foster social and cultural respect for fetal personhood. The making of the unborn patient through clinical and technical means and the emergence of fetal personhood were thus intimately linked in Liley's work. He saw his mission extending beyond the clinical domain into the political sphere, both participating in anti-abortion politics and serving as a "scientific" spokesman (sic) for the fetus. In what became an oft-cited quote in the anti-abortion movement in New Zealand, he (Liley 1971d:12) remarked that "it is a bitter irony that just when the fetus achieves some medical status and importance there should be pressure to make him a social non-entity."

---

[38]Title taken from McCarthy (1983), writing in New Zealand's major pro-life newsletter on the occasion of Liley's death in 1983.

[39]Dr. John Simpson, Senior Vice President of the Queensland Right to Life Association, introduced Liley as keynote speaker at the University of Queensland, July 15, 1980.

Displaying a certain biological determinism, Liley drew upon his clinical work to articulate notions of the "natural" fetal patient, a status which he then used to legitimate fetal personhood in both clinical and cultural spheres. Beginning with his Rh work, Liley saw himself primarily as a physician to the fetus which he viewed as his primary work object. For example, he (1971:13) wrote, "We can now diagnose and treat a number of fetal maladies, and the list is growing...The fetus can be sick and need diagnosis and treatment like any other patient." In an anti-abortion newsletter, he (Liley n.d.a) elaborated the issue as such: "This is the fetus we look after in modern obstetrics, the same baby we are caring for before and after birth...This is also the fetus whose existence and identity must be so callously ignored or energetically denied by advocates of abortion." An important aspect of achieving fetal patienthood, and consequently fetal personhood, was elucidating key physiological characteristics of fetal development and behavior which seemed to support this emergent status. Yet in order to establish fetal patienthood, the fetus needed first to be framed as a distinct individual, separable and separate from the pregnant woman in whose body it resided.

Reverberating with echoes of Liggins' (1972) research on the fetus' definitive role in onset of labor, Liley presented the fetus not only as a distinct patient, but as *actively* in charge of pregnancy. For example, in a paper originally presented in 1975 Liley (1983:6) wrote, "Our new human has in hand even grander designs and undertakings than simply his own internal organization and development. He also develops his own life-support system, his placenta, and his own confines...But even the organization of his own confines does not exhaust the list of achievements of our new individual. His own welfare is too important to permit leaving anything to the chance cooperation of others, and therefore he must organize his mother to make her body a suitable home." Among the ways in which Liley claimed fetuses accomplished this were by producing chorionic gonadotrophin to prevent menstrual shedding of the endometrium, taking over the endometrium, manufacturing hormones necessary for

pregnancy, preventing immunological rejection by the host mother, and determining the duration and onset of pregnancy. In short, according to Liley (1983:8), "the fetus is a young human, dynamic, plastic, resilient, in command of his own environment and destiny with a tenacious purpose."

These fetal representations formed the core of Liley's (1972b) classic article, "The Fetus as a Personality," in which he presented "a day in the life of a fetus."[40] He suggested:

> we may not all live to grow old but we were each once a fetus ourselves. As such we had some engaging qualities which unfortunately we lost as we grew older. We were physically and physiologically robust. We were supple and not obese. Our most depraved vice was thumbsucking, and the worst consequence of drinking liquor was hiccups not alcoholism...Is it too much to ask therefore that perhaps we should accord...to fetal personality and behavior, rudimentary as they may appear by adult standards, the same consideration and respect? (Liley 1972:105)

Contradicting earlier pre-modern conceptions of the fetus as a passive *tabula rasa* in the uterus, Liley constructed it as "very much in command of the pregnancy" (1972:100). His account of fetal personhood is replete with action verbs: the fetus "guarantees" the success of pregnancy, "induces" changes in maternal physiology,

---

[40]This article was subsequently reprinted in the inaugural issue of *Fetal Therapy* (Liley 1986), with the following introductory note from the editors (Michejda and Pringle 1986b): "Sir William Liley was one of the fathers of fetal therapy...His untimely death in 1983 robbed the field of fetal therapy of a mentor of incredible experience, breadth of vision and wisdom. This paper was based upon an invited paper delivered to the Eighth Annual Congress of the Australian and New Zealand College of Psychiatry in October, 1971. A wide variety of facts about fetal physiology are reviewed, exploding the myth of the fetus as a passenger carried to term, and pointing out that the fetus is an active, developing individual responding to his environment in ways designed to improve his comfort. Liley's humor and tremendous breadth of knowledge are both amply illustrated in this article. He is sorely missed."

"determines" the duration of pregnancy, "decides" which way he [sic] will present in labor, "learns" and "responds" to stimuli, and so on.[41] The pregnant woman in this account is reduced to a "suitable host," "the space and shape available to [the fetus]," "the walls of the fetal world," "a pregnant uterus," and "a plastic, reactive structure."

Liley's representations of fetal individuality are significant in terms of establishing historical foundations of the paradigm of maternal-fetal conflict which undergirds contemporary practices.[42] In much of this literature, as illustrated in the above examples, pregnant women are relegated to the status of maternal environments or hosts for the developing, active fetus. Liley (1983:6) wrote, "Women speak of *their* waters breaking and *their* membranes rupturing, but such expressions are so much nonsense--these structures belong to the fetus." He (Liley 1971d:12) later asserted that "at no stage can we subscribe to the view that the fetus is a mere appendage of the mother...The early embryo stops mother's periods and induces all manner of changes in maternal physiology to make his mother a suitable host...It is argued that the fetus is incapable of independent existence. However, the fetus can outlive his mother, and dead women have been delivered of live babies. Independent existence is a relative concept."[43] This notion of separate entities with distinct interests extended beyond physiological matters. Liley often discussed abortion in terms which exalted fetal rights and privilege and trivialized women's own concerns and needs: "We have the rather perverse situation nowadays where the perfectly

---

[41]See Casper (1994) for a discussion of these issues in relation to theoretical conceptualizations of human and non-human agency.

[42]This is discussed more fully in Chapter 6.

[43]Liley (1983:7) also wrote, "This relationship between a baby and his mother is clearly much more than simple biological parasitism. The term parasite, so frequently applied to the fetus, is often used, not in the limited biological sense, but with the sociological overtone of describing someone who takes all and contributes nothing. Neither sense is applicable to the fetus. True, he is parasitic on mother for his nutritional requirements. In the same sense many wives could be said to be parasitic on their husband's income; but just as wives would indignantly maintain that they contribute much to a home and a marriage to justify their keep, and that really what is involved is a division of labor, so also does the fetus justify his keep by organizing and maintaining his pregnancy. Such a relationship is more accurately described as parabiosis or symbiosis, and physiologically there is no question who guarantees its success."

healthy are clamouring for their abortions on the grounds of the inconvenience they represent to them...It's not continuation of the pregnancy which represents any threat whatsoever to anyone; it is the life of the child which represents a threat to somebody's convenience" (Liley 1979).

In addition to the significance of physiological understandings of fetal life, Liley's clinical work and his anti-abortion activism were mutually reinforcing in another important way. He became quite distressed that certain techniques he had developed to save fetal lives were subsequently used in abortion practices. Specifically, he was upset that amniocentesis, a "life-saving diagnostic tool" in his view, was "next misapplied to detect handicapped unborn so they could be destroyed--a 'search and destroy mission'" (McCarthy 1983:5). This was a particularly salient issue for Liley, who with his wife, Margaret, had adopted a little girl with Down's Syndrome in 1976. He was a passionate advocate for the rights of the disabled and mentally handicapped and often remarked that "the morally handicapped cause far more misery and suffering in the world than the mentally or physically handicapped ever do" (Liley 1971a:3).[44]

He was especially disturbed by the application of techniques he developed for transfusions in administering solution for saline abortions. Liley (1971c:3) wrote, "A living fetus may be dismembered, poisoned or ejected to die from exposure but this must be called 'terminating a pregnancy,' not exterminating a fetus. The subterfuges necessary to maintain this approach are well seen in my own hospital where the needles used for the infusion of hypertonic saline, 7" Tuohy needles or trochars and cannulae, are the needles we originally developed for fetal transfusion." From these

---

[44]In a series of papers written in the late 1970s and early 1980s, Liley articulated both a scientific and a social vision of "mental retardation." For example, Liley (1980b:1) wrote "It is with slender qualifications and no great self confidence that I introduce the vitally important topic of the social integration of the victim of Downs Syndrome. I can speak only as a parent, a taxpayer and a sympathetic observer." Writing about medical research on retardation and the effects of antenatal diagnosis, he (Liley 1982:9) stated "When the prevailing message is that it would be the end of the world to have a child with Downs Syndrome, the young and unsuspecting parents who produce the majority of these babies could be forgiven for thinking it is the end of the world. In this climate the task of achieving a bonding and avoiding rejection of a desperately needy baby, of replacing self pity with a positive approach is made doubly difficult."

quotes, one gets a sense of Liley's bitterness at this perceived "misappropriation" of fetal technologies for other than life-saving purposes.

To some degree, Liley's views on abortion were shaped by collaboration with his wife, Margaret, who shared his political perspective. An obstetrician and pediatrician, and a publicly recognized mother of six children, Margaret was considered an expert on pregnancy and fetal life, although her career was overshadowed by Liley's.[45] For many years in the 1960s and 1970s, she was Director of the Antenatal Clinic at National Women's Hospital, where she was responsible for patient education and instituted a number of innovative procedures, such as allowing newborn babies to remain with their mothers to facilitate bonding.[46] She co-authored two well-received books on pregnancy (Liley and Day 1966; Day and Liley 1968),[47] and enjoyed a reputation throughout New Zealand as an obstetrical authority. Yet to some extent, despite her own considerable accomplishments, Margaret's renown rested on her relationship with Liley, a common position for wives of famous men. For example, in the introduction to Margaret's first book, Virginia Apgar (Liley and Day 1967:viii) wrote: "Her understanding of life before birth is enhanced by a working alliance with her husband, Dr. A. William Liley, a world-renowned obstetrician who developed the daring procedure of intra-uterine transfusions for infants threatened by Rh complications...From these combined vantage points, she views the infant world

---

[45]Pat McCarthy told me, "[Margaret] was very highly qualified in her field, and I think that perhaps she felt that she was overshadowed by Bill."

[46]Margaret Liley (1966:xii-xiii) described this work in her first book: "In our hospital in Auckland, New Zealand, [we put] infants with their mothers as soon after the birth as the mother's condition would permit, so that the mother would know the baby, and know how to care for him when she took him home...We found, however, that most young mothers were not equipped to receive their infants. The majority had never held a baby...Many mothers were frankly fearful of the tiny strangers they had produced...It was at this time that we created an ante-natal program designed to teach mothers about their babies--both unborn and newborn."

[47]In 1967, "Margaret Liley made history when she and her co-author, Miss Beth Day, of New York, gave a press conference from her Epsom home over two linked telephones with a gathering of medical reporters and science editors in New York to launch Dr. Liley's book *Modern Motherhood*...The press conference lasted an hour, with questions from New York being answered in Auckland. Later that day Dr. Margaret Liley told me how the children (they have two sons and three daughters) had been sent to school early and the family poodle locked up to ensure quietness--but the poodle broke loose and barked and scratched at the door" (Anonymous 1972:83).

imaginatively, yet realistically, providing fresh insights for the medical profession as well as for potential parents."

Margaret Liley's books are striking in the degree to which they mirrored some of Bill Liley's writings about fetal development and personhood. In *Modern Motherhood*, Margaret introduced her subject by situating pregnancy and fetal life within the context of new techniques in medicine which focus on the fetus. She (1967:xiii) wrote, "Among the many fascinating discoveries that we see among our babies, I think the most important is that each baby is an individual. It is separate and distinct from every other individual, in fact, much earlier than anyone suspected. In treating the unborn we have found that the human fetus possesses distinct characteristics from about the fourth month of intra-uterine life, before his mother even feels him." Throughout the text, she (1967:23) refers to the fetus as "active, lively [and] independent," a "tiny Tom Thumb of a human being [who] dominates his environment."

An entire chapter is devoted to "The Fetus as an Individual," and is rife with phrases similar to Liley's notions of the fetus as a personality. The "unborn baby" is described as distinct and separate from the mother, with needs of his (sic) own: "Fetology...holds many secret parcels...There will be greater awareness that it is the baby who conducts the orchestra in pregnancy, and that we should be able to predict his condition more accurately by studying the ways in which he is affecting his host's body" (1967:213). Margaret Liley believed quite firmly that clinicians and researchers should attempt to understand as much as possible about fetal life. She (ibid.) writes, "It seems ironic that we can know more about the minute-to-minute physiological condition of our monitored astronauts, whirling around in space thousands of miles away from us, than we as yet know about the unborn baby who lies but an inch or two away from our eyes...The challenge facing medicine today is to make [pregnancy and

birth] less of a mystery, and, as the shrouds surrounding pregnancy are pushed back by science, to let the miracle be even more clearly seen."

In addition to drawing on the same cultural repository of ideas about fetal life, Margaret also shared Liley's sentiment that abortion was wrong. She firmly believed that fetuses were individual personalities and that abortion destroyed "unique human lives." For example, during our visit together in 1994, she brought out a series of chalk tracings that she and Liley had made on the basis of fetal x-rays. Apparently, Liley had saved hundreds of fetal x-rays discarded by radiologists who no longer needed them for diagnostic purposes. The chalk tracings, in bright colors on dark construction paper and resembling a child's crude artistic efforts, were used by Margaret in educational presentations about pregnancy and fetal life. She told me, while tracing the drawings with her fingers with a sort of radiant fascination playing across her face, that both she and Liley loved the images because they showed the fetus as active and moving. She contrasted their chalk images with the famous photographic representations in *A Child Is Born* (Nilsson 1990), saying that because those images were based on dead fetuses they were "static and lifeless." Although she and Bill Liley shared the belief that the fetus was a human being worthy of medical treatment and protection, Margaret Liley did not share the public spotlight focused on her husband's anti-abortion activities. She had no involvement in his more visible efforts although, as Pat McCarthy told me, "She supported him in what he was doing."

Liley's position on abortion often posed difficulties at National Women's Hospital, particularly for colleagues who did not necessarily share his views. For example, Florence Fraser accepted the premise of fetal personhood, remarking that "I became aware of the fetus as an individual early on...They've always been personalities to me, they've always been people from a very early stage. I guess it was Bill's influence right at the beginning of my obstetrics career, you know he sowed

the seed." Yet Fraser, whose obstetrical training in Britain had included abortion procedures, disagreed with Liley about the morality of abortion. She told me, "Bill didn't like abortions at all...I had done abortions in Britain...In those days, here in New Zealand, you didn't get many abortions done because the law had not been liberalized at all...I've never been as rigid as Bill was about abortion because of the women, but he wasn't even keen on sterilization. And we did have a few words about that."

Liggins, with whom Liley shared so many interests, was also not involved in abortion politics. When I asked him if he had a role in the anti-abortion group Liley formed, he replied, "No, no. I have always steered well clear of any political position." Yet not everyone at National Women's Hospital disagreed with Liley. Indeed, when he organized the Society for the Protection of the Unborn Child (SPUC) in 1970 there was considerable interest among many of his colleagues. Harvey Carey, Herb Green, and Ross Howie were all early supporters of the effort. Howie recalls, "Liley focused on the rights of the fetus, and we agreed that you can't bump off the fetus or unborn to solve social problems." In part, the emergence of anti-abortion sentiment among some medical practitioners during this period was a reflection of developments in New Zealand's abortion law, which was becoming increasingly liberalized.[48]

As a British commonwealth, New Zealand's law was very similar to Britain's, which prohibited abortions in most cases prior to 1967. In 1967, in both Britain and New Zealand an act was passed allowing abortion for the mental and physical health of the pregnant woman. Doctors began liberalizing their practices in response, and abortion clinics were established in urban areas. Shortly after the 1967 act was passed, "a private abortion clinic was set up in Auckland, and it was fairly clear that abortions were being performed without too much regard for the law. The law was being interpreted fairly broadly. The doctor who was performing abortions at that

---

[48]Pat McCarthy, a member of SPUC and editor of New Zealand's anti-abortion newsletter, *Humanity*, provided background information on abortion law in New Zealand.

clinic, Dr. James Woolnough, was prosecuted. He stood trial three times, but was acquitted. Abortion was a tremendously political issue at that time."[49] In 1976, the government set up the Royal Commission on Contraception, Sterilization, and Abortion, which after a year of deliberations further liberalized abortion law. The current situation, according to McCarthy, is such that "if there's anyone who wants an abortion, they can likely get one."

Witnessing the liberalization of abortion laws in New Zealand, as well as the creation of the pro-choice Abortion Law Reform Association in the late 1960s, prompted Liley, Dr. Patrick Dunn, and Leo Manning to form SPUC in 1970.[50] According to SPUC literature, the society is "a humanitarian organization, formed out of concern at the increasing disrespect for the value of human life. [It] is involved in various programs to educate the public regarding the humanity of the Unborn Child and the fundamental value of all human life, assist the mother and child, and lobby for protective legislation."[51] McCarthy states that SPUC's mission is "respect for life across the board" including resistance to euthanasia, even though its name evokes only abortion. When the abortion issue was more acutely politically charged in 1970, membership in SPUC peaked at about 50,000, but is now about 20,000. McCarthy laments that SPUC has not made much of a national impact, as "abortion figures have gone up from about 3,000 per year during the Royal Commission. An official report from 1992 states it is 11,460. That's still low by comparison to the U.S., but very high compared to what the abortion rate in New Zealand used to be."

As President of SPUC for many years, Liley was far more than a figurehead. He had by this time fashioned himself into a national and international activist for fetal

---

[49]Op. cit. note 48.

[50]Dunn was a retired obstetrician who still served as a consultant to National Women's Hospital and Manning was a local Jewish businessman. Liley served as SPUC's first president, and all three men became active campaigners on behalf of the organization.

[51]Included among its publications are pamphlets on the psychological and physical effects of abortion and on fetal development.

rights. According to McCarthy (1983:5), "he campaigned throughout the country and far beyond for recognition of the unborn child as a human being with inalienable human rights." Yet his activism was not limited to SPUC activities. In many instances, he spoke or gave testimony as a scientific and medical expert on the fetus. Liley was seemingly always willing to speak on behalf of fetuses, often at a moment's notice. McCarthy (1983:5) relates a story of Liley being in the middle of a surgical operation when a call came in from the U.S.; "five hours later he was on a plane to give evidence before a district federal court in Rhode Island." In testimony before the U.S. Senate Judiciary Subcommittee on a proposed constitutional amendment to protect fetal life, Liley took great pains to establish his professional credentials. He remarked, "I am a registered medical practitioner in New Zealand...Clinically I have worked as a fetal pediatrician for most of the last seventeen years...In 1963, I developed a method by which Rh babies beyond the aid of conventional therapy could be given transfusions in utero."[52] His "expert" status gave Liley a cushion of legitimacy in his role as spokesman (sic) for the fetus, allowing him to move comfortably between his clinical work and his political activities.

Liley was aware that there was considerable animosity aimed at him for his stand against abortion in New Zealand. Several people relayed one of Liley's favorites stories, involving some negative graffiti sprayed on a local bank about him. His children, most of whom kept their money in that bank, went in and complained; within a few hours "the wall was whitewashed." As discussed above, some of his colleagues disagreed with his position, and this often made collaborative work more difficult. Although his clinical work was deeply respected among the broader medical community, his political views may have impeded professional advancement. For example, Bernard Nathanson, a major anti-abortion figure in the U.S., remarked "Liley

---

[52]Presented at hearings of U.S. Senate Judiciary Subcommittee on Constitutional Amendments, May 7, 1974.

should have won a Nobel Prize for his pioneering work in fetology...I am always surprised that he has not...He is truly one of the great men of medicine."[53] Given the international recognition Liley achieved, one might speculate that it is his political work and its association with the controversial issue of abortion which prevented his being awarded any major prizes.[54]

Despite resistance from some of his colleagues and controversy stemming from his political activism, Liley continued to advocate for fetal rights until his death in 1983. In part, this is because he felt that he had no choice *but* to be a spokesman for the fetus, a position which rendered pregnant women invisible. The fetus, in his view, is "small, naked, nameless, and voiceless. He has no one except sympathetic adults to speak up for him and defend him--and equally no one except callous adults to condemn and attack him."[55] Yet the tension between his convictions and their public reception often put Liley under a great deal of stress. Reid (1973:8) reported that Liley's "deep study of fetal medicine...has created a moral conviction that he must educate the public about his findings on the status of the fetus and a certainty that it must have social and legal protections. Results?...A load of responsibility that gives his face an unusually greyish tinge for a comparatively young man." A number of informants remarked that toward the end of his life, Liley seemed particularly worn down and depressed. Although nobody will ever know for sure, it is not unreasonable to suspect that stress engendered by his dual roles as both medical practitioner and political activist contributed to his death.

It is both ironic and tragic that Liley, who had such deep and abiding respect for life, would take his own.[56] Given the public pro-life stance he maintained for years,

---

[53]Quoted in an article entitled "Why No Nobel?," November, 1981. The name of the newspaper in which this article appeared was not available on the copy I was given by Pat McCarthy.

[54]Clarke (1990, 1996) has argued that nobody gets the Nobel Prize for reproductive work because its association with sexuality renders it controversial and illegitimate.

[55]From "The Humanity of the Unborn," which appeared in an anti-abortion newsletter.

[56]Liley committed suicide on June 15, 1983, by drinking a glass of cyanide at his home in Auckland. His wife, Margaret, was home at the time and found his body shortly thereafter. Although I discussed his

Liley's suicide was greeted with shock and disbelief by his family, friends, colleagues, former patients, the anti-abortion movement, and the media.[57] Reaction to his death provided a fitting elegy for the feto-centric work to which he dedicated his life, often stressing his political activities over his biomedical contributions. For example, a colleague in the anti-abortion movement remarked, "It won't be for his professional achievements that we remember Bill so well--rather for his humanness, his magnanimity and good humor...It was as though this great man, filled with care and compassion for the tiniest humans (the unborn) extended that warmth and care to all...He had a unique and facile ability to present the unborn as a living individual, unique and precious." John Willke, at that time President of the U.S. National Right to Life Committee, wrote to Margaret, "We were shocked to receive the news of Bill's death. He was such a good guy, so firm and consistent in his values and so vitally important to all of us in our struggle to save babies." Margaret Tighe, Chair of the Australian Right to Life Committee, wrote to Margaret also: "We are all very saddened and shocked that our movement has lost a man whom we regarded as its Father." According to Liley's close colleague Herb Green (1986:22), "his last reward was to be described at his funeral...by the Dean of Auckland's Holy Trinity Cathedral, in the presence of both the Roman Catholic and Anglican hierarchies, as a true agent of God."[58]

---

suicide and the possible reasons for it with many of my informants, I do not feel it is my place to convey the information I obtained. Even ten years later, his family and colleagues remain profoundly affected by the circumstances of Liley's death. However, two items are relevant to the story of fetal surgery that I have presented here. First, Margaret told me that Liley had been depressed for months before killing himself, causing his superior at National Women's Hospital to suggest he step down. According to Margaret, this was about the worst thing that could have happened to a "workaholic" like Liley. Second, one informant told me that Liley had been more eager to adopt their daughter with Down's Syndrome than Margaret had. The double tragedy of Liley's suicide, according to this informant, is that "in killing himself, he forgot about [his daughter]."

[57]Liley's obituary was carried in newspapers across New Zealand, as well as internationally. In one article, the parents of Liley's first successfully transfused baby, Grant Liley McLeod, remarked, "We were really dumbfounded. He was too young to die, and he had too much to offer."

[58]The anti-abortion newspaper *Humanity* (July 1983) reported on Liley's funeral: "On June 18, a bleak mid-winter's day, grieving prolifers joined representatives of the Government and Opposition, university and hospital staff, and colleagues and friends of Sir William as they crowded into the Anglican Holy

In sum, Liley's political commitments, like his medical accomplishments, left a lasting legacy. The imbrication of his medical work with the politics of reproduction played a significant role in the making of the unborn patient. Liley's clinical achievements resonated throughout the political arena in which fetuses were granted autonomous personhood and constructed as worthy of protection and advocacy. Perhaps anti-abortion groups on their own would have made a conceptual connection between Liley's medical work and their own organizing efforts in the 1960s and 1970s. Yet because Liley was overtly political and had colleagues in many social worlds, he clearly facilitated the transmission of his work into other arenas. He acted as a conduit of sorts, translating and interpreting medical work on fetuses into the more accessible cultural and political language of fetal personhood. In this process, Liley's generic fetus underwent several ontological iterations, from a natural object in the womb to the fetal patient to a full-fledged member of the human community. Below, I explore additional sites where a similar transformation occurred, namely New York and Puerto Rico, through open fetal surgery efforts both in animals and in humans.

"A Bona Fide Patient": The Emergence of Open Fetal Surgery in New York and Puerto Rico

Despite the extraordinary success and allure of Liley's transfusion work, there were a number of clinical problems identified with this approach to fetal treatment (Adamsons, Freda et al. 1965; Adamsons 1966). For example, locating the peritoneal cavity of the fetus was often quite difficult, as discussed above. On many occasions, the "blind" needling technique resulted in injury to fetal organs. In addition, even if the

---

Trinity Cathedral in Auckland with members of his family for a memorial service. 'You and I are mesmerized by this tragic loss,' said Dean John Rymer, a SPUC patron, who conducted the service...In his panegyric, Dr. Herbert Green, a colleague and friend, spoke of Sir William's prowess as a great scientist and great teacher, his human qualities and his concern for the unborn...The Anglican Archbishop of New Zealand, Archbishop Paul Reeves, presided and the administrator of the Catholic diocese of Auckland, Bishop John Rodgers, was present. Sir William is survived by his wife and scientific co-worker Margaret, Lady Liley, and by their six children."

peritoneal cavity was adequately penetrated with needles and catheters, absorption of injected red blood cells was not always successful. Repeated punctures were often necessary because of the decay of the donor cells and expansion of the intravascular compartment of the fetus. If the fetus survived, exchange transfusions were almost always required after birth. Thus, although Liley's *closed* intrauterine transfusion method was life-saving in many circumstances and avoided the problems associated with surgically opening the uterus, as Adamsons (1966:204) pointed out "large variations in salvage rate exist[ed]" with this technique. In an attempt to increase survival rates and expand treatment to a larger group of fetuses, Adamsons, Freda, and others began pursuing *open* fetal surgery for exchange transfusions in Rh cases in New York and Puerto Rico. Open surgery promised enhanced visibility of and access to the fetal patient.

In order to fully understand the concurrent emergence of open fetal surgery in New York and Puerto Rico, and how this was shaped by reproductive politics, it is first necessary to situate Puerto Rico as a U.S. colony. Throughout the nineteenth and twentieth centuries, there has been considerable political, economic, cultural, scientific, and human migratory traffic between the U.S., especially New York, and the small, beautiful Caribbean island which historically has been viewed as "a strategic outpost" for U.S. interests (Ramirez de Arellano and Seipp 1983:4). Puerto Rico was ceded to the U.S. as a spoil of the Spanish-American war in 1898, and subsequently suffered from the "imperialism of neglect" by a country that did not know what to do with its newest geographic outpost. Predominantly Catholic with an economy supported by coffee, sugar, and tobacco, Puerto Rico soon began to appeal to certain U.S. constituents who advocated for a greater stateside role in the island's affairs. It became known in the 1950s as the "TVA of the tropics" (Ramirez de Arellano and Seipp 1983:88), amenable to innovative social and economic policies designed to enhance the welfare of its inhabitants and bolster the island's economy. Currently a

self-governing protectorate of the U.S., Puerto Rico struggles for autonomy within a geopolitical context shaped by its history as a colony.

It is within this broader context that the relationship between Puerto Rico and research institutions such as Columbia University developed. Puerto Rico *qua* colonial possession has been "studied and restudied" (Ramirez de Arellano and Seipp 1983:ix) serving as a sort of natural laboratory for research of all kinds on both human and non-human primates.[59] Health issues, including reproduction, have been central to U.S./Puerto Rico relations, beginning in the 1930s and 1940s with scientific interest in tropical diseases and one of the earliest programs of surgical sterilization for contraceptive purposes. For example, Columbia and its affiliate, the School of Tropical Medicine at the University of Puerto Rico, instituted a trial birth control clinic in 1935 and began a large-scale, island-wide birth control program shortly thereafter. In addition, the birth control pill was tested first in Puerto Rico in the mid 1950s, in part because the island was both crowded and impoverished, providing a rationale for limiting its population (Ramirez de Arellano and Seipp 1983; Oudshoorn 1994). In sum, Puerto Rico, in concert with key locations in the U.S., has long been an important site for certain types of scientific and medical work. Because Puerto Rico has been configured as a "natural laboratory," it has often been possible for scientists to engage

---

[59]A primate colony called Cayo Santiago was established in 1939 by the School of Tropical Medicine, an adjunct of Columbia University. Located off the southeast coast of Puerto Rico on a 37-acre island, the colony was originally stocked with over 400 Rhesus monkeys, 14 gibbons, and three macaques transported from India (Rawlins and Kessler 1986). In 1951, control of the colony passed to the School of Medicine, which struggled to maintain it adequately as the island was insufficiently capable of sustaining the food requirements of its inhabitants. Upon visiting the island, one researcher wrote, "The colony appeared in lamentable condition. There was evidence of malnutrition, cannibalism, and the island was infested with rats, which would beat the monkeys in a struggle for coconuts. The delivery of food from the shore was irregular and inadequate and there was evidence of water shortage" (Rawlins and Kessler 1986). During this period, many monkeys attempted, mostly unsuccessfully, to escape the island by swimming to the mainland. As Backman (1982) argues, an influx of NIH money in the 1950s provided necessary resources and rejuvenated a tenuous research program. Haraway (1989:22) discusses Cayo Santiago in the context of the use of the Rhesus monkey as a "standardized research monkey." She also traces the relationship between Columbia University and the School of Tropical Medicine at the University of Puerto Rico, a partnership shaped by a convergence of interests in reproductive physiology, naturalistic behavior studies, and infectious diseases. In 1970, the UPR School of Medicine resumed control of Cayo Santiago and integrated it into what is now called the Caribbean Primate Research Center (CPRC). The addition of a veterinarian to the CPRC staff in 1977 facilitated a new focus on noninvasive biomedical research on free-ranging Rhesus monkeys (Rawlins and Kessler 1986).

in research that might be precluded by institutional barriers present on the mainland. This more "relaxed" investigative climate rendered Puerto Rico a fertile setting for the emergence of experimental clinical practices such as open fetal surgery.

Monkeys, Medical Work, and the Fetal Patient: Experimental Open Surgery in New York and Puerto Rico

The development of open fetal surgical techniques, then, resulted from a confluence of traffic, both human and non-human, between New York and Puerto Rico. Adamsons, Freda, and a group of lesser known surgeons in San Juan, Puerto Rico, were all key actors in this enterprise. Prior to beginning work on open fetal surgery, Adamsons had long been interested in obstetrical techniques relating to problems of the fetus. While a resident in 1958-59 he worked with renowned fetal physiologist Dawes at Oxford, with whom Liggins had also worked, where he "spent a productive year studying fetal breathing in sheep." There he learned that sheep are able to tolerate surgical intrusion because they have a different kind of placenta and fetal compartment: the junction between the placenta and fetus is very unstable in sheep, unlike in primates where placenta and fetus are closely linked. On the basis of their physiological research in sheep, both Dawes and Adamsons were invited to Puerto Rico to work with Rhesus monkeys in a small primate colony run by William Mendel.[60] At the time, Mendel was working on oxygenation experiments in which monkeys were suffocated by placing condoms over their heads. In the spirit of this research, Adamsons and Dawes began experiments in which fetuses were lifted out of the uterus and exposed to cooler air in order to study neonatal asphysia and resuscitation. They were encouraged by their results that they could open the uterus

[60]The small primate colony, or research supply laboratory, was located on the medical campus of the University of Puerto Rico. It was supplied with Rhesus monkeys obtained from Cayo Santiago.

and not be faced with irreparable technical problems, such as premature labor or immediate fetal demise.

After finishing his residency at Columbia in 1961, Adamsons again returned to Puerto Rico, this time to work on developing chronic preparations in Rhesus monkeys. Mendel was no longer head of the primate center, having been replaced by Ronald Myers, a neurophysiologist trained at Johns Hopkins and Chicago. Adamsons approached him with the idea of drawing blood samples from monkey scalps to measure oxygenation. In the U.S., Adamsons told me, this was seen as controversial because "nobody knew what the contributions of such research were," but in the more relaxed experimental climate of Puerto Rico the research proceeded with little controversy. As a result of these experiments, Adamsons learned, among other things, that fetal tolerance to physical intrusion into the primate uterus was greater than previously thought. He (1966:204) wrote, "it could be shown that even in the monkey, complete removal of the fetus and its subsequent replacement to the uterine cavity is compatible with fetal survival, and even repeated exposures of the fetus during the course of the development are feasible."

In the meantime, Freda was busily investigating Rh disease at Columbia, where he was on the obstetrics faculty. This work subsequently led to the development of Rh immunoprophylaxis, discussed above. He was quite interested in pursuing additional avenues of fetal treatment, and had done some limited animal experimentation on techniques for locating the placenta and uterus for penetration with needles. As a practicing physician, Freda already had extensive experience with obstetrical procedures such as cesarean section. When Adamsons returned to Columbia in 1962, he became very interested in Freda's Rh work. After hearing of Liley's work, Adamsons and Freda had begun thinking about catheterizations for infusion technology using open surgical techniques. Adamsons told Freda about his research in Puerto Rico and how tolerant the monkey fetus was of intrusion. This,

coupled with Freda's technical expertise in maternal patients, persuaded the team that they should "find a willing patient" and proceed apace.

Shortly after deciding to follow this course, Adamsons and Freda located a suitable patient. As Adamsons remembers, "we were surprised when the mother readily agreed, but also nervous and anxious." The following is a description of the open fetal surgery performed on the 33-year old woman, who was in the fourth month of her eleventh pregnancy:

> The abdomen was entered with a vertical midline incision...The incision was carried down to but not including the membranes...The membranous sac was then dissected free of the uterine wall...This allowed the membranous sac to bulge out through the incision along with the foot of the fetus...the sac was incised over the foot and then the leg of the fetus was immediately delivered up to the groin...A cut down on the femoral artery of the fetus was carried out through a small incision over the femoral triangle...A 22 gauge polyethylene catheter was inserted into the femoral artery and the exchange transfusion was carried out through this approach...Following the exchange transfusion a purse-string suture was placed about the incision encompassing the membranes and a small portion of the myometrium. The purse string was pulled closed as the leg of the fetus was replaced into the uterine cavity with a negligible loss of amniotic fluid. The remainder of the incised myometrium was closed in two layers (Freda and Adamsons 1964:819-20).

The procedure lasted three hours, and both the pregnant woman and her fetus appeared to tolerate it well. Adamsons remembers, "We were ecstatic. We felt that the next step was going to Stockholm to win the Nobel Prize." Unfortunately, the woman went into labor two days after surgery and, after premature vaginal delivery, the baby died of immaturity and incomplete expansion of the lungs. Yet on the basis of prior amniocentesis, Adamsons and Freda had predicted that this fetus would have died anyway within two and a half weeks of diagnosis. Thus, despite the baby's death, they considered the procedure successful in terms of providing valuable information about open surgical techniques.[61]

Freda and Adamsons (1964) claimed there were several advantages of open surgical exchange transfusion, including introducing the greatest volume of fresh Rh negative blood into the fetal circulation, insuring the broadest protection for the fetus for the longest period of time, and obviating the need for repeated "blind" needling attempts and possible fetal damage. They identified the two largest disadvantages as technical difficulties in carrying out the procedure with minimal trauma to the pregnant woman and her fetus, and the possibility of premature labor following the operation. The physiological tendency in primates once the uterus is opened is initiation of labor. In this initial surgical case, as in later cases in New York and elsewhere, premature labor proved to be a recalcitrant problem in open fetal surgery. Unlike Liley's representations of pregnant women as passive bystanders during pregnancy, premature labor frames women as active participants, at least physiologically.

Columbia Presbyterian was an ideal place to pursue this research, as the patient population was steady, diverse, and large, with about 20 patients per month referred for Rh problems. At that time, before the routinization of intraperitoneal

---

[61]Despite Freda and Adamsons' claim that the procedure was successful, the pregnant woman whose baby died most likely did not view it as such. In relating this story to me, Adamsons also subtly shifted the blame onto the woman, remarking (emphasis added) that "the woman went into labor, *without telling us about her uterine contractions.* Even though the baby was not anemic or hydropic, it died from prematurity after a vaginal delivery."

transfusions in clinical practice, Columbia was the only place in the world outside New Zealand where they were being done. Yet, according to Adamsons, there were differences in the patient population which suggested a different therapeutic trajectory. In New Zealand, Liley was treating patients at early gestational ages, allowing for greater absorption of blood into the fetal peritoneal cavity. In New York, many patients were already too far advanced for intraperitoneal transfusions. Adamsons stated, "We had no other choice but to do open surgery for transfusions." Yet despite fertile conditions for the emergence of this work, Adamsons and Freda had little success with open transfusions. There was not a single surviving fetus in the first few years of their work, beginning with their first attempt in 1963.

In 1964, while Liley was also at Columbia, he, Adamsons, and Freda engaged in considerable exchange of information. The latter researchers were interested in learning more about Liley's closed intraperitoneal transfusion technique, and Liley was curious about their open surgical procedure. Adamsons remembers Liley fondly, remarking that "he was a nice person and we got along well." Freda talked about his work with Liley that year in positive terms, stating that they had spent a lot of time discussing animal research and obstetrical techniques in humans. Yet despite this spirit of collaboration, there were differences among the three men. According to Florence Fraser, Liley was "very scathing of Adamsons' work on open transfusions." Open surgery was never pursued at National Women's Hospital in Auckland because of concerns about maternal and fetal risk. Liley (1968) wrote that "Adamsons' and Margulies' isolated success using hysterotomy to implant intraperitoneal catheters does little to redeem the consistent failures of Freda and associates." It is interesting to speculate, given Liley's views on open surgery, about some of the discussions he may have had in 1964 with Adamsons and Freda.

In addition, after 1964 the working relationship between Freda and Adamsons began to sour. They had, at this point, attempted surgery in a handful of additional

patients, with little success. According to Freda, he did not want to "go public" with their research on open surgery because of its controversial nature; he "wanted to keep it quiet until we got more pieces under our belt." He turned down an interview request from *Time*, and was both surprised and furious to discover an article in that magazine the following month with Adamsons "all over it. As if Adamsons had done the surgeries or provided the patients." Freda became angry with Adamsons for publicizing their research and for taking credit for the surgery. He told me that he had been the main surgeon, with colleagues Albert Plentl and Adamsons assisting. Freda retaliated by denying Adamsons access to obstetrical patients at Columbia Presbyterian. This incident marked the end of their collaboration, although according to Freda, he and Adamsons "are friendly now."

Adamsons, who left Columbia shortly thereafter to work at Mt. Sinai and then chair the Department of Obstetrics and Gynecology at Brown University, began collaborating with a team of physicians in Puerto Rico who were interested in open fetal surgery. He tells of a woman with a poor history of Rh treatment who presented in San Juan with a grossly hydropic fetus. Using open surgical techniques, Adamsons and his colleagues injected red blood cells directly into the fetus' bone marrow, administered the hormone thyroxin to accelerate fetal growth and development, and successfully delivered a live baby three weeks later. This operation marked the beginning of extensive collaboration between Adamsons and his colleagues in Puerto Rico, which continued long-distance until Adamsons became Chair of Obstetrics and Gynecology at the University of Puerto Rico in 1976.[62]

---

[62]Adamsons still holds this position. In discussing his tenure at the University of Puerto Rico, he provided insight into the different working conditions which affect reproductive research. In Puerto Rico, he has access to primate colonies and is able to see patients "who actually need medical care, rather than just reassurance like in the U.S." The institutional review board is "very helpful and open" at UPR, there is a steady supply of patient and research subjects, and he has ample time for basic scientific research in addition to his clinical education responsibilities. On the flip side, however, incomes are smaller, resources are slim, and national funding is insufficient for the scope of research he would like the department to engage in. For example, although the primate colony is accessible, there is not always enough money to actually carry out projects using Rhesus monkeys. Because of these "trade-offs" between greater control over research and limited resources in a clinical setting, Adamsons feels that research has

The Puerto Rico team, sans Adamsons, had made its own contributions to the emergence of fetal surgery by performing the first *successful* open surgery for transfusion. Building on the efforts of Liley, Adamsons, and Freda, as well as a substantial body of monkey experiments, Asensio and his colleagues (1966) carried out an open intrauterine exchange transfusion in 1965 on a 26-year old woman with Rh complications. The following is a description of the procedure, notable for its similarities to Freda and Adamson's description cited above:

> Under fluothane anesthesia, a routine approach for cesarean operation was carried out...A verticle (sic) uterine incision 4 cm. long was made on the right anterior wall of the corpus...The membranes were exposed and gently separated from the underlying decidua...The amniotic sac was incised and the left leg delivered up to the inguinal area...A lead for fetal electrocardiogram was applied to the fetal heel for continuous monitoring of fetal heart rate...A cut-down was done with exposure of the great saphenous vein just below its junction with the femoral vein. A No. 22 polyethylene catheter was inserted into the great saphenous vein and secured into it. An exchange transfusion of 160 c.c. of fresh O-negative citrated packed red cells compatible with maternal serum was carried out (1966:1130).

After closing the uterus in layers, as in cesarean section, the woman was placed on antibiotics and monitored closely. Twenty days after the operation, the woman went

---

suffered at UPR; he remarked that he and his faculty have a lot of abstracts and presentation papers that never get published. He summed up the situation by saying, "Salaries are between 1/6 and 1/10 what they are on the mainland. But I can't compensate economic loss with intellectual scope. I can't yet convince the faculty that there's something valuable about intellectual satisfaction...Maybe some of my ideas will be taken over by students who go on to do other work."

into labor and, 36 hours later, delivered a "living female infant in good condition" (1966:1130). For the most part, Asensio and his colleagues followed the procedures established by Adamsons and Freda, with a few modifications. Buoyed by this success, Asensio et al. (1966:1133) wrote, "The absence of premature labor, the minimal trauma sustained by the fetus, and the relatively long-term correction of the anemia have led us to believe that this procedure might be the safest and the one that can provide most definite treatment for the severely affected erythroblastotic fetuses." Even Liley (1968:56) was impressed, stating that "Asensio's single success remains the only convincing rescue by intrauterine exchange transfusion." Despite their achievements, however, Asensio and his team did not pursue open surgery beyond their first and only successful episode, for reasons which are unclear.

Ironically, following this effort in Puerto Rico and some clinical interest in the work of Adamsons and Freda, open fetal surgery was not pursued again until the early 1980s. There are a number of possible reasons for this. First, Liley's technique of intraperitoneal transfusion was seen as both effective and safe enough that open surgery for erythroblastosis was viewed as excessively invasive. According to Michejda and Pringle (1986b:8), "If the group in Auckland, New Zealand, had not been so outstandingly successful in the development of percutaneous fetal transfusions, then fetal surgery would have had to have developed to a point where major fetal surgery could have been routine by this time." Another explanation for this lag is that preventive measures such as anti-D immunoprophylaxis drastically reduced the incidence of Rh disease, which prior to ultrasound was one of the only conditions amenable to diagnosis by amniocentesis (Michejda and Pringle 1986a). Until new conditions became diagnosable, physicians had no impetus for pursuing open surgical treatment. For these and other reasons, open fetal surgery enjoyed a brief but intense wave of interest in the 1960s which had subsided by the end of that decade.

Although open fetal surgery has not been consistently pursued since its experimental nascence in the 1960s, like Liley's technique it profoundly influenced the development of fetal medicine (Michejda and Pringle 1986a). The act of opening the womb and removing the fetus was nothing short of amazing. Both controversial and fascinating, open surgery had a number of indirect consequences for reproductive medicine, the most significant being its role in the making of the unborn patient. In Adamsons' view, the importance of fetal surgery was in defining the fetus as "a bona fide patient, as much a patient as the mother is, available for diagnosis and treatment." In retrospect, he sees the medical work of the 1960s as "breaking down barriers of the fetus as a patient. There is nothing more convincing than opening the uterus, taking the fetus out, and putting it back. This makes other procedures, both diagnostic and therapeutic, more acceptable."[63] In other words, privileging the fetus as a patient and pursuing fetal surgery served to legitimate other, less invasive fetal treatments. Yet despite this legitimating function, open fetal surgery in New York and Puerto Rico was shaped also by controversy and its "illegitimate" association with reproductive politics.

"Not God's Will": Reproductive Politics in the Origins of Open Fetal Surgery

Unlike Liley, neither Adamsons nor Freda were centrally involved in abortion politics. This is somewhat surprising, given that the abortion context in the U.S., including Puerto Rico, was similar to the New Zealand situation historically. Throughout the 1960s, abortion was illegal in most states. Yet a rising tide of liberalization legislation at the state level had already begun, with New York among the most progressive states. Petchesky (1990) argues that these changes were fueled by (some) women's changing status in the U.S., government interest in

[63]Legitimacy goes both ways, however. According to Adamsons, "once the field was opened with amniocentesis, percutaneous umbilical sampling (PUB), and other techniques, people couldn't argue against invading the womb. People had to accept that the uterus was no longer a sanctuary."

population control, lack of a coherent policy on sexuality and reproduction, and a number of other factors. Because these conditions were already in place in New York, the 1973 Supreme Court decision legalizing abortion,[64] rather than instigating widespread transformations in abortion practices, merely served to legitimate existing practices. In other states, however, *Roe v. Wade* served as a catalyst for many significant changes in abortion practices.

The situation was similar in Puerto Rico, reflecting the island's status as a U.S. colony. Abortion was a criminal offense until the law was relaxed in the mid-1960s, followed shortly thereafter by the legitimating effects of *Roe v. Wade*. Given the intense Catholicism of Puerto Rico, abortion has always been a deeply contested moral and political issue despite its eventual liberalization. In the 1930s, abortion was a "back-street procedure, shrouded in secrecy and sidestepped by both physicians and politicians as a controversial issue" (Ramirez de Arellano and Seipp 1983:144). In the 1950s, there were approximately 5,000 abortions each year in Puerto Rico's hospitals. By the 1960s, women from the U.S. mainland began flooding the island's clinics in order to obtain abortions, increasing the annual number of abortions to around 10,000 (Ramirez de Arellano and Seipp 1983). This practice became so prevalent that these trips were known as "San Juan weekends," modeled after the "Havana weekends" that had been popular prior to the souring of U.S./Cuba relations. By 1980, when a Federal court decided that the extant Puerto Rican abortion law was actually more permissive than the Federal standard, abortion was legal (although not always accessible or affordable) at any point during pregnancy.

It is interesting to speculate about why Adamsons and Freda were not involved in abortion politics during such social and legal ferment. Perhaps because change was already on the horizon, they felt no inclination to get involved in the often heated abortion debates, regardless of their personal beliefs. In later years, as

---

[64]United States Supreme Court, *Roe v. Wade*, 1973.

abortion became liberalized, both Adamsons and Freda, as practicing obstetricians, performed abortions in their own practices. Also, working in New York and Puerto Rico, they saw a diverse group of women with a range of reproductive needs shaped by race and class. What is clear is that neither man shared Liley's deep personal faith in fetal personhood and his corresponding anti-abortion sentiment. Indeed, Adamsons told me that he has never had the same political convictions that Liley had about abortion. Nor does he believe that open fetal surgery is particularly ethically problematic. He remarked, "In the U.S., we're willing to invest lots of money, time, and resources to save one life. [Fetal surgery] is showing that we can salvage an organism that would otherwise die...It is not unethical to be changing nature in the interests of Homo sapiens."

Yet despite Adamsons' claims that there were few ethical issues, controversy pervaded open fetal surgical efforts in a number of ways. Where Liley's work fascinated and was well-received, open fetal surgery was seen from its inception as quite controversial. According to Adamsons, many physicians "felt like it was sacrilege to open the uterus, not God's will." There was concern from obstetricians about maternal morbidity and mortality, as well as worry about how fetuses would be affected by invasive treatment. The political climate surrounding fetal research at that time, including its evocation of abortion politics, made this type of work extremely contested, as we saw in Chapter 2. Adamsons believes that during the 1960s, the medical world collectively labeled such research as "too political, intrusive, and weird." Indeed, Adamsons' and Freda's own department chair resisted publication of the results of their initial open surgery experiments for about six months, until *after* news of Liley's achievements with intrauterine transfusion technology had spread. As Adamsons pointed out, "Once Taylor [the Chair] learned that other institutions were doing this also, some of the slack went up over the work at Columbia."

Adamsons recounts that when he was at Columbia, he was considered "a Nazi" and "mentally incompetent" for suggesting that some fetuses resulting from superovulation be killed. He remarked, "There was a medieval notion that the uterus is a sanctuary, and it is not God's will to invade." This was "extraordinary" to him, because he wanted to consider the fetus "as a bona fide patient" which he could diagnose and treat. His efforts to do so were continually met with skepticism and resistance. For example, while at Mt. Sinai from 1970-75, Adamsons encountered tremendous opposition from the institutional review board for wanting to inject drugs into the amniotic fluid in investigations of fetal growth. It was not until he moved to Puerto Rico, with its more relaxed atmosphere, that he was able to expand his work using thyroxin for stimulating fetal maturation. Adamsons' research was poorly received by most American journals, which he felt was due to the political nature of his work on human fetuses. As a result of this unenthusiastic reception, he published many of his studies in German and Scandinavian journals. It was not until 1993 that he was invited to write something in a U.S. journal, a bitter irony for the man who wrote a provocative introduction of open fetal surgery in the influential *New England Journal of Medicine* in the mid-1960s (Adamsons 1966)

Controversy pervaded this type of work in other ways, as well. Adamsons related a story about non-human primate research that illustrates the contestation surrounding experimentation on fetuses. Given how little fetal research was going on in the U.S. at that point (see Chapter 2), there was considerable interest in Adamsons' primate research in Puerto Rico, in which he was opening the uterus and removing the fetus for experimentation. *Life* heard about this work and asked if they could send a reporter and photographer. Adamsons and his colleagues agreed, but realized that the large number of research projects at Cayo Santiago limited the availability of monkeys to use in the photo shoot. So Adamsons, his team, and the *Life* crew traveled to the Oregon Primate Center in Beaverton, which was interested

in expanding its funding base by generating interest in primate research. The subject of the resulting *Life* story was "taking a fetus out of the uterus for research;" the images are of "a monkey fetus lying next to the uterus." Adamsons pointed out that "they had to make sure the photograph included the monkey tail in the picture to identify it as an animal--we did not want to be accused of human experimentation!"

In sum, although these men were not actively involved in the abortion debates, Adamsons' and Freda's medical work was nonetheless shaped by its association with the politics of reproduction. They pursued open fetal surgery within a context in which abortion was still illegal but gradually being liberalized. Concern about experimentation on human fetuses made physicians and other interested actors less receptive to *open* fetal surgery than they had been to Liley's closed technique. Although the more relaxed institutional climate in Puerto Rico facilitated certain types of research, it did not fully insulate Adamsons, Freda, Asensio, and their colleagues from downstream reactions to open fetal surgery in humans. It is not unreasonable to suspect that the two-decade lag between these efforts in the 1960s and later work on open fetal surgery was, in part, due to the influence of reproductive politics. Ironically, however, the legacy of medical work and scientific research which eventually culminated in renewed efforts in the 1980s was imbued also with the spirit of controversy. Although it may have legitimated other, less invasive forms of fetal treatment, open fetal surgery itself has been pervaded by an essence of illegitimacy.

Conclusions

In this historical account of the emergence of fetal surgery in the 1960s, I have shown how medical work intersected with the politics of reproduction in the making of the unborn patient. By following the work done on and with fetuses, the coalescence of human actors, non-human research materials, technologies, scientific knowledge, geographical locales, institutional settings, and political agendas is made visible.

Prior to the work of Liley, Adamsons, Freda, and their many colleagues, fetuses were not considered patients in the ways they subsequently came to be perceived later. The work described here, including Rh studies, intrauterine transfusion technology, and open fetal surgery, shaped the development of fetal medicine in profound ways. By breaching the womb and "revealing" the fetal work object, the human actors profiled in this account paved the way for the emergence of a clinical entity called the fetal patient and a social entity called the fetal person.

Because of the close interweaving of medical work, itself a social endeavor, with the politics of reproduction, the debut of each these twin entities occurred almost simultaneously. It is crucial to examine not only "just the facts" of what happened in each location historically, but also how the intersection of medical work with the politics of reproduction shaped the practices discussed here. Although the making of the unborn patient historically has been marked by controversy and illegitimacy, the history of the unborn patient is also the history of the fetal person legitimated and naturalized by scientific medicine. By focusing on the fetal work object, this chapter has illuminated how cultural and political perspectives on the fetus permeate medical work, and how representations and consequences of medical work flow out of the operating room into other arenas of social life.

To return to the historiographic problem with which I introduced this chapter, what are we to make of Liley's place in history, assigned by his progeny, as the "father" of fetal surgery? Surely if he developed closed techniques and others were working on open techniques for fetal transfusion, there must be many primogenitors of what we now recognize as fetal surgery. Although Liley's work came first chronologically and had a tremendous impact on clinical and cultural views of the fetus, Adamsons and Freda first attempted open surgery, unsuccessfully, and Asensio and his colleagues followed with a successful effort. In part, they were able to do this because, as obstetricians, these men knew *how* to open the uterus, Adamsons from

Rhesus monkey research and Freda, Asensio, and the others from years of clinical obstetrical practice. Throughout, all of these efforts were collective and required the participation of a range of medical workers with different skills and contributions.

In terms of awarding "discovery" of fetal surgery, then, the picture is somewhat murkier than the historical record to date has allowed. Liley's work, supported and enabled by his numerous colleagues and patients, was seen as seminal because it was the first attempt to breach the womb. Yet it was followed closely by medical work which breached the womb in even more profound ways, not only opening the uterus but removing the fetus for treatment. With each iteration of fetal treatment, the fetal work object became increasingly more visible and accessible. What is distinctive about fetal surgery is not that one great man was responsible for its emergence, but rather that a heterogeneous group of practitioners working in different places collectively built a new specialty. All of the medical work discussed here provided a foundation for the emergence of contemporary fetal surgery and notions of the fetus as a patient.

In the next chapter, I discuss in greater depth the relationship among clinical practices, scientific knowledge, and technologies in forging a link between the historical efforts of the 1960s and a resurgence of interest in open fetal surgery in the early 1980s.

Chapter 4

A Hybrid Clinical Practice: Intersections of Medicine, Science, and Technology in Fetal Surgery

"Medicine isn't a coherent whole. It is no unity, but an amalgam of thoughts, a mixture of habits, an assemblage of techniques. Medicine is composed of many ways to handle bodies, observe pictures, make numbers, conduct conversations...Medicine is rich with differences."
(Mol and Berg 1996)

Distinctions among medicine, science, and technology are made often in social and cultural studies of these practices. For example, medicine and clinical research have long been conceptualized as applied sciences not worthy of analytical consideration within science studies (Casper and Berg 1995). On the other hand, while medical sociologists have focused a great deal of attention on medicine and health care, they have often ignored its scientific and technical contents. Ironically, despite sustained attention to what distinguishes these different sets of practices in both medical sociology and science studies, within an array of local settings they often overlap considerably, mutually shaping each other. This is clearly evident in the historical account of fetal surgery presented in Chapter 3. The doing of science is virtually impossible without varied sets of specific knowledges, tools, and technologies; technological development often rests on research into what works and does not work; and medicine is shaped by diverse clinical, scientific, and technical practices. In short, none of these practices exists within a vacuum; rather, each overlaps and is contingent with the others within specific domains of practice.

Clinical research (or experimental medicine) is a particularly useful site for studying the imbrication of medicine, science, and technology in practice. Rather than thinking of such research merely as applied science, however, it is more useful to think of this kind of work as a *hybrid clinical practice*. Framing it this way, rather than as a

hybrid *scientific* or *technical* practice, highlights the eventual downstream applications in treating human patients. Clinical research is heterogeneous in nature, comprised of medical work both with and on patients, scientific experimentation on human and non-human research subjects, and a host of biomedical technologies brought to bear on the task at hand. Contrary to the common assumption that clinical practice necessarily follows from basic research or technological development in a causal, unidirectional fashion, I argue that there is rather "*n*-way" traffic among these different practices. While much clinical practice may be built on basic scientific work, insights from clinical experience are often carried back into the laboratory, provoking further investigation. In addition, while technologies may make certain clinical practices possible, and even spur the emergence of new fields, their utility is only evident and analyzable within the settings in which they are used. Technologies develop in tandem with, and not necessarily prior to, other work practices within particular domains.

In this chapter, I investigate these issues through an analysis of the hybrid nature of experimental fetal surgery. I focus on both the linkages and fluid distinctions among medicine, science, and technology as each set of practices is used to achieve access to the fetal work object. Rather than assuming that these are discrete sets of practices, my analysis illustrates how the borders between what we think of as medicine, science, and technology are porous, overlapping, and shifting. By concentrating my analytical lens on all of the work done in fetal surgery, I am able to see the many different types of practices involved in making this medical specialty possible. Moreover, examining these different practices as they relate to the specialty as a whole brings into sharper focus some of the reproductive politics infiltrating and shaping the work of experimental fetal surgery. Chronologically, this chapter serves as a bridge of sorts between the historical work discussed in Chapter 3 and the re-emergence of open fetal surgery in the early 1980s, discussed in Chapters 5 and 6.

More specifically, I address four related aspects of fetal surgery in order to analyze and showcase its heterogeneous nature. First, I discuss the significant role of fetal physiology in the emergence of fetal surgery and argue that fetal physiological insights from earlier decades have been reconfigured and marshaled in the service of contemporary practices. Second, I address the influential role of ultrasound and other diagnostic technologies in the emergence of fetal surgery. Without resorting to a technologically determinist argument, I suggest that the lag between fetal surgery in the 1960s and contemporary efforts may be explained in part by the absence of diagnostic technologies prior to the introduction of ultrasound. Third, I examine the use of research animals, especially sheep and monkeys, as experimental work objects, focusing on their important participation in the development of the field. Last, I explore fetal wound healing research as exemplary of the basic research/clinical practice continuum; this experimental paradigm illustrates quite graphically the multi-directional nature of hybrid clinical practices. All of these practices, in different yet intersecting ways, have participated in the making of the unborn patient through facilitating and mediating access to fetuses as biomedical work objects.

From the "Stone Age" to the "Bronze Age" of Experimental Fetal Surgery: The Significance of Fetal Physiology

Fetal physiology has been central to the development of fetal surgery. Because of the nature of such research, and the ways in which it has been pursued across time, key aspects of fetal physiology have permeated all subsequent fetal practices within medicine and science. As we saw in Chapter 3, Liley, Adamsons, Freda, and others were quick to integrate physiological understandings into their work, often working closely with fetal physiologists such as Liggins. Yet despite the significance of fetal physiology in the twentieth century, contemporary fetal surgeons were initially slow to recognize its usefulness for their own clinical practice. They

toiled in relative ignorance or avoidance of physiological principles until persistent fetal deaths and high maternal morbidity persuaded them to review and adopt physiological ideas. In listening to the voices of fetal physiologists, fetal surgeons ultimately transformed experimental fetal surgery. In the words of Jack Nelson, a fetal surgeon, physiology ushered fetal surgery out of the "stone age" and into the "bronze age."

In general, fetal physiologists seek to understand normal vital processes in fetuses, such as growth and development, as well as mechanisms of pathology. The "father" of fetal physiology, Sir Joseph Barcroft, and his colleagues, including Donald Barron at Yale and Cambridge, performed the first experiments in fetal physiology in the 1930s, focusing on physiological function in fetal lambs (Longo 1978). The next wave of fetal physiologists, led by Geoffrey Dawes at Oxford, continued studies of function and also expanded investigations to encompass other problems, such as fetal blood circulation. Joseph Sigler, a preeminent fetal physiologist who began his career under Dawes, told me, "Originally we did pretty simple procedures and then as we began to recognize that it was possible to do much more extensive procedures, we expanded our horizons and did a whole variety of studies on fetal function." Subsequent avenues of research in fetal physiology included cardiovascular disease, hormones, the role of the placenta, and the intricacies of the birth process.

Historically, fetal physiological research has been shaped in many ways by limited access to fetal work objects and by other related constraints, including intense controversy over non-therapeutic research on living human fetuses (Steinbock 1992; Maynard-Moody 1995). Given these constraints on practice, most fetal physiological research uses either animal models, often sheep and non-human primates, or human fetal tissue obtained from abortions, miscarriages, ectopic pregnancies, and stillbirths. Historically, the development of techniques permitting research on exteriorized (out of the uterus) living fetuses still connected to the placenta provided for a greater

investigative range. Sigler vividly remembers this early work: "It was possible to exteriorize the fetus and the uterus did not contract actively. So that it was possible therefore to study the fetus while it was still attached to the placenta...[Dawes and his colleagues] were the first people who really explored this. And all their studies were done of exteriorized fetuses." Sigler also stated that in most instances, the fetuses died shortly after being removed from the uterus, thus providing only a limited time frame within which to conduct experiments. Some physiological research has also been performed on living fetuses in utero, as, for example, in conjunction with therapeutic interventions or through the use of diagnostic technologies such as ultrasound, fetal blood sampling, and fetoscopy.[1]

In shifting their attention to the birth process, fetal physiologists became interested in fundamental processes of the fetus as an entity located inside a pregnant woman's body. The functional basis of the maternal-fetal relationship, especially the role of the placenta, became a primary research concern (Dancis 1987). Physiologists investigate, for example, placental transfer of key molecules (Boyd and Sibley 1989), regulation of amniotic fluid (Abramovich and Page 1989), regulation of fetal growth (Johnson and Greenberg 1987; Fowden 1989), and cardiovascular function. One reason physiologists give for studying such processes is that understandings of maternal-fetal function are claimed to provide insight into fetal adaptation mechanisms that occur at birth. When a fetus is born, a host of intricate physiological changes are believed to take place. The neonate's body must quickly assume functions which were regulated during the fetal state by the placenta, including circulation, oxygen provision, enzyme and hormone regulation, and temperature control. According to Dr.

---

[1]Fetoscopy is a technique in which a fiber optic endoscope is used to view the placenta and fetus and to collect fetal blood samples for both diagnostic and research purposes. According to Daffos (1991:75), "before 1982, [fetal] blood sampling was performed by fetoscopy, which is a difficult and invasive technique that has a significant associated fetal risk...The ability to sample pure fetal blood under ultrasound guidance has completely changed this situation and has provided ready access to new information in fetal medicine."

Sigler, "this is an area which still requires a great deal of exploration as to what is removed from the fetus and newborn when the placenta is removed."[2]

Ironically, physiological research on the maternal-fetal relationship produces consequential constructions which contribute to ambiguity surrounding definitions of prenatal life.[3] By focusing on the transformation from fetus to neonate, physiologists foster the perception that "the fetus is steadily approaching a boundary--the beginning of life beyond the womb, the termination of being unborn" (Grobstein 1988:107). This boundary is defined in the U.S. as fetal *viability*, a nebulous concept that shape-shifts according to the latest technoscientific advances.[4] According to Grobstein (1988:109), "fetal 'viability' refers only to capability to survive disconnection from the placenta." Thus, research exploring the intricate mechanisms of the autonomous fetus, symbolically and materially detached from a pregnant woman's body, propels fetuses closer to the viability boundary by shifting the biological parameters of existence. These constructions are consequential for fetal research and treatment practices in which human fetuses are worked on, as well for practices in other domains in which the fetus is situated, such as abortion politics.

In addition to understanding and defining normal developmental processes, fetal physiologists are also concerned with the pathology of fetal function, an area of

---

[2]This implies that scientists might want to recreate some of these maternal physiological processes in order to sustain life outside of a woman's uterus via construction of a *techno-uterus*. Indeed, there have been attempts in the biological sciences to create artificial wombs, placentas, and uteri, none of which have proven successful in practice (Borrell 1989; Hartouni 1991).

[3]Through explorations of prenatal life, fetal physiologists define the physiological parameters of human existence. Physiological research produces some familiar fetal constructions, such as the division of pregnancy into stages (usually classified as trimesters) based on fetal development. Physiology offers us the preembryo (zero to two weeks), the embryo (three to eight weeks), the early fetus (nine to twenty weeks), the middle fetus (twenty-one to thirty weeks), and the late fetus (thirty-one weeks to birth) (Grobstein 1988:131). These boundaries are designed to clarify fetal status and are based on scientific accounts of organogenesis, behavioral function, movement, and other "natural" indicators. Such constructions are often deployed in other practices, such as legal and ethical domains, in attempts to resolve controversies over the significance of fetal life (Casper 1993).

[4]Parameters of fetal viability, or survivability outside of a woman's body, shift in relation to technological "advances" in fetal medicine and neonatology. Currently, fetal viability is considered to be between twenty-three and twenty-four weeks (Grobstein 1988; Morowitz and Trefil 1992), a "fact" highly relevant to fetal research and treatment in utero as well as to abortion debates.

research which has had considerable impact on experimental fetal treatment. Physiologists study problems such as abnormal labor, preeclampsia, the etiology of congenital malformations, perinatal brain injury, and diseases of major organs (Kretchmer, Quilligan et al. 1987; Harrison, Golbus et al. 1991). One practice used to investigate these topics is simulation of abnormal conditions in fetal work objects, usually non-human animal models constructed in the laboratory. For example, interest in congenital heart problems led one physiologist to manufacture lesions in sheep in order to study the effect of fetal defects on cardiovascular development. This technique is also used in fetal surgery and wound healing research, where sheep, non-human primates, and other animal fetuses are injured prenatally, repaired, and delivered for investigative purposes. The nature of these practices suggests that they would be highly controversial if performed on human fetal work objects, and often are controversial even when animal models are used (Brans and Kuehl 1988).

In short, the materiality of human fetal work objects, including their often inaccessible location inside pregnant women's bodies, renders them inappropriate for much fetal physiological research. Such constraints on practice have limited the types of questions scientists ask and the means by which they attempt to find answers, compelling researchers to develop alternative practices using non-human animal models and/or dead human fetal material. Despite these constraints, contemporary fetal physiological research provides a toolbox for understanding and defining prenatal life which is used also in other practices organized around fetal work objects, such as fetal surgery. If fetal constructions are located at the intersection of diverse sociotechnical practices, including physiological research, then technoscientific accounts carry greater weight because they rest on presumably natural "facts of life" (Morowitz and Trefil 1992). In the late twentieth century, fetal physiologists are engaged not only in penetrating "the darkness of the womb to illuminate what is

within," but they are also, in significant and consequential ways, "choosing human futures" (Grobstein 1988:ix).

Given the claimed importance of fetal physiology, it is ironic that contemporary fetal surgeons did not immediately recognize its relevance in their own work. In the early 1980s, when the second wave of human fetal surgery began, surgeons had already executed a large number of experimental surgeries in research animals. Yet they had not systematically applied much less integrated long established knowledge from human fetal physiology. As fetal surgeon Jack Nelson remarked, "In the stone age days, we weren't making an effort to understand the physiology. We didn't know the techniques to do these things...It became clear to me after seeing the first couple of cases that we didn't know what we were doing from a physiologic point." Fetal physiologist Joseph Sigler echoes this assessment: "One of the problems is that they were looking at this purely from the surgical point of view...They had little appreciation for what the physiological issues were." In short, there were sharp distinctions between fully understanding how fetal bodily processes work and merely fixing fetal anatomical problems surgically. The connection between physiological understandings and better clinical outcomes had not yet been made.

Building on experimentation in animals (mainly sheep), fetal surgeons had moved ahead in the early 1980s with clinical work in human patients, with little regard for some of the key physiological issues and consequences involved in opening the uterus and removing the fetus. The primary concern, which was salient in the 1960s and remains a problem even today, is that once the primate uterus is surgically opened it has a tendency to go into labor. Because surgeons attempt to replace the fetus within the pregnant woman's womb after surgery, controlling preterm labor is fundamental to performing this procedure. But without physiological understanding of what *causes* preterm labor, fetal surgeons were helpless to *control* it. Jack Nelson recalls, "So we're operating on this organ nobody understands, flat out, nobody

understands it. The consequences of that are we're doing what we *thought* was right: relax the uterus, do the operation, close the uterus, and get out. We didn't know what we were doing, we still don't know what we're doing with the placenta...There is no doubt that nobody understands anything at all about perioperative fetal physiology."

In terms of the trajectory of fetal surgery, then, fetal surgeons pursued clinical experimentation despite significant kinks that had not yet been worked out physiologically. Because they had figured out how to perform fetal surgery in a technical sense, and could do it with what they saw as reasonable success, they were encouraged to continue even in the absence of physiological tools. However, ongoing clinical experience made them aware of their predicament regarding fetal physiology; only in retrospect were they able to see how it might be useful in their work. As fetal surgeon Tony Murphy pointed out, "As is so often the case, you know a little bit of knowledge and you're very dangerous. You perturb one part of the system and the whole things goes haywire because you don't know what you're doing." Lack of surgical success and the increasing complexity of fetal surgery compelled the surgeons to investigate other avenues, including physiological approaches. Thus, as fetal surgeons continued to have major problems with preterm labor and fetal mortality, they eventually turned to fetal physiology for answers. Dr. Sigler points out, "When [fetal surgeons] began to make some measurements and recognize that the fetus was not doing well, that was when they began to look for advice about what one could explore as possible avenues of improvement."

It is critical to situate these developments within the organization of medical specialties. Most fetal surgeons have in-depth specialty training in surgical techniques and little training in physiological principles beyond basic pre-clinical medical education. They see themselves as "fetus fixers" rather than as interpreters of physiological clues, more Indiana Jones than Sherlock Holmes. Attempting to understand the basics of fetal physiology meant acquiring a new set of skills and

knowledges with which to approach their work. Dr. Nelson stated, "We're now at the point where we want to understand the physiology too. It was such an enormous undertaking early on that to have gone back to try to understand the physiology would have slowed it down by a decade or more...At the time they had had success in sheep...And they didn't think they needed to go back and understand the physiology. Nobody had thought of the question because they didn't know the issue existed. It's only now that we realize the issues exist and we have to answer the questions as well as ask them." There is now a general consensus that applying physiology to enhance clinical practice has made at least a minimally positive improvement in terms of fetal survival.

There is a further important professional dimension to these physiological issues, as well. While fetal surgeons did not immediately recognize the need for understanding basic physiology, another set of medical workers had been consistently applying physiological principles in their clinical work. Obstetricians have a solid understanding of the physiology of the maternal/fetal relationship and the birth process which emerged historically from their clinical focus on taking care of pregnant women. Given fetal surgeons' relative lack of knowledge about these issues, one might think that they would have looked to obstetricians for advice and collaboration in attempting to solve the preterm labor problem. But this was not the case. Rather than recognizing that obstetricians possessed a set of skills and ideas that could be useful, fetal surgeons opted instead to define physiology as a battleground upon which to struggle with obstetricians over who would control and define the nascent specialty of fetal surgery.

When fetal surgeons first became interested in open fetal surgery in the early 1980s, they assumed that obstetricians were expert in certain aspects. For example, they believed obstetricians were skilled in surgically opening the uterus, something the fetal surgeons feared they might not be able to learn how to do. Early blueprints of

the division of labor had obstetricians opening the uterus to make the fetus available and closing it again after the fetal surgeons completed their detailed manipulations. Over time, however, as part of an interdisciplinary team exposed to all aspects of fetal surgery, fetal surgeons became convinced that they could learn to do what obstetricians had traditionally done. Moreover, as Dr. Nelson claims, "it turns out that [obstetricians] don't necessarily know what they're doing, that they don't necessarily understand what they're doing. Because nobody understands perioperative maternal/fetal physiology...It is clear after extensive discussions with them that they don't understand the physiology behind it." Thus, the complexity of fetal surgery and its physiological challenges serve as a sort of lever with which fetal surgeons have attempted to wrest management of the pregnant woman away from obstetricians.

Nelson illustrates this particularly well in discussing how a renowned fetal physiologist at Hilltop Hospital was enrolled as an ally by the fetal surgeons: "Dr. Sigler is now an intimate part of the perioperative management...The really good thing about getting him involved was to get all these different groups to change their focus...His life's work has been understanding fetal physiology; now he has the opportunity to see it applied to human fetal surgery...It has been his influence, as one of the most respected basic scientists in the field, that has allowed us to make changes against the obstetricians' will. The obstetricians can't argue, they just can't. It's like, when you're overshadowed, you're clearly outclassed. They just can't argue. So it's going in the right direction now, it's just going to take time. And politics is the biggest risk right now; egos are involved."

Fetal surgeons have thus pursued a dual strategy of simultaneously denigrating obstetricians' skills and knowledge in the realm of physiology and embracing physiological principles as their own province. Karl Hansen, a fetal surgeon, describes this process: "The obstetricians have painted themselves into a

corner. They're frozen and unable to change, unable to adapt, unable to improve the patient's care, and unable to understand the physiology...So my biggest contribution has simply been to go back, review the physiology of mom and fetus, and try to understand what we're doing...We've made dramatic improvements in what we understand now...We've also learned that there's a lot of things we don't know and we will have to do the experiments." To some degree, fetal surgeons' efforts to freeze out obstetricians have been successful. Obstetrician Liz Amos told me that fetal surgeons seem more comfortable working with perinatologists rather than obstetricians, and at Hilltop Hospital management of the preterm labor problem has been handed over to perinatologists. These specialists, focused on the maternal/fetal unit, serve as middle-ground facilitators between fetal surgeons, who see the fetus as primary work objects, and obstetricians, who view pregnant women as primary work objects (see Chapter 5).

In sum, fetal physiology has been a key element in the emergence of experimental fetal surgery. Medical workers in the 1960s, as we saw in Chapter 3, worked closely with fetal physiologists in crafting fetal treatment technologies. Contemporary fetal surgeons, although slower to grasp the significance of a physiological approach, nonetheless subsequently incorporated physiological principles and ideas into their work. In an effort to improve outcomes through addressing the preterm labor problem, fetal surgeons turned to an established knowledge base in fetal physiology, as well as to specific fetal physiologists for advice. Jack Nelson remarked, "Once entering this bronze age, where we understand some physiology and we're able to use some techniques to monitor mom and fetus, we'll learn enough to enter the next stage where we can do better." Yet fetal surgeons may have been after something else in their turn to physiology: legitimacy.[5]

---

[5]Historically, there has been a surprising lack of application of physiology in clinical practice. For linkages between physiological research and clinical practice, especially legitimacy issues, see Geison (1979, 1987).

By embracing basic scientific research in the form of fetal physiology, fetal surgeons were not only able to claim improved outcomes, they were also at least partially successful in defining fetal physiology as their turf, thus providing a scientific basis for fetal surgery. This display of professional territory-building potently illustrates the imbrication of science and medicine in clinical practice, as well as some consequences of these dynamics.

Seeing Into the Womb: The Significance of Prenatal Diagnostic Technologies in Experimental Fetal Surgery

Where fetal physiology offered a cloak of scientific legitimacy for experimental fetal surgery, prenatal diagnostic technologies, especially ultrasound, have provided a different kind of boost. Since the development of prenatal diagnostics, there has been a significant relationship between testing and subsequent treatment. As we saw in Chapter 3, amniocentesis was a key element in early efforts to transform fetuses into patients. By analyzing amniotic fluid, Liley and his colleagues attempted to determine which fetuses were at risk for hemolytic disease before treating them through intraperitoneal transfusions. In amniocentesis, fluid is withdrawn from a pregnant woman's amniotic sac transabdominally using a large needle, usually during the second trimester of pregnancy although it is now being performed as early as the 12th week of pregnancy (Gilbert 1993). The fluid, which contains fetal cells, is then cultured and analyzed, particularly for chromosomal anomalies and neural tube defects. Because amniocentesis is usually performed later in pregnancy, it raises troubling social questions about when women can make an informed and legal choice about continuing a pregnancy (Rothman 1986).

A somewhat newer technique called chorionic villus sampling (CVS) can be used early in the first trimester and is thus often seen as an alternative to amniocentesis. Like amniocentesis, CVS is used to diagnose genetic abnormalities.

In CVS, a catheter is inserted through a woman's cervix and directly into the chorion, the outermost fetal membrane. Villi, or small hair-like projections on the surface of the membrane, are removed using a syringe, then separated from maternal tissue and cultured. Although it decreases the time required to diagnosis abnormalities, CVS also has a higher miscarriage rate than amniocentesis and may cause birth defects (Gilbert 1993). Significantly, although both amniocentesis and CVS are *invasive* diagnostic technologies and thus invoke maternal and fetal safety issues, explicit discussion of these concerns is often muted.[6]

A third diagnostic technique, a simple blood test of the pregnant woman, is still experimental but could potentially avoid the risks of spontaneous abortion because there is allegedly less danger to the fetus than with other techniques.[7] In this procedure, technicians sift through a sample of maternal blood using cell sorters to find the small number of fetal cells that migrate through tiny fissures in the placenta. The fetal cells are then examined for genetic abnormalities using a technique called fluorescent in-situ hybridization (FISH), which marks certain chromosomes for viewing under a special microscopic light (Roberts 1991). Unlike amniocentesis and CVS, which are common but not yet routine, a diagnostic blood test could easily become an integral part of prenatal care. It would likely be less expensive (and thus more accessible to women of lower economic classes), could be done earlier in pregnancy, and may be used in conjunction with other blood tests to determine the health status of a pregnant woman and her fetus. All of these diagnostic technologies have been integral to the emergence of fetal treatment practices, especially to fetal surgery which required direct access to the fetus for intervention.

In contrast, the most significant technology, ultrasound, differs from amniocentesis and CVS in that it provides a *visual* window into a pregnant woman's

---

[6]Gilbert (1993) provides a rare frank discussion of risk in prenatal diagnosis.
[7]See Associated Press (1991).

uterus, offering pictures of her fetus and its organs. The use of sonographic technology in fetal medicine has expanded considerably since the 1970s. Ultrasound has become, in the U.S., a routine part of prenatal care for most women.[8] Marwick (1993:2025) states that "by allowing visualization of the developing fetus, ultrasound represents a major advance in perinatal care." Ultrasound images are used to detect anomalies in fetal growth, to expose birth defects, to "see" how many fetuses there are, to determine gender, and to otherwise ascertain "normality" in pregnancy. Ultrasound's use in diagnosing fetal abnormalities usually centers on structural and/or organic problems rather than genetic defects. Structural defects in fetal organs are often clearly outlined in ultrasound images, paving the way for attempts at treatment. Because structural defects are most amenable to surgical treatment, ultrasound has been particularly instrumental in the emergence of experimental fetal surgery.

Ultrasound was originally developed as a technique for detecting submarines during W.W.II (Oakley 1984). Just as ships and submarines are able to detect other vessels in the water surrounding them, ultrasound enables physicians to peer into the womb by bouncing sound waves off structures suspended in amniotic fluid. Despite its complex military origins, this now secularized technique is relatively simple to perform. A pregnant woman, having consumed massive quantities of water, lies on her back with her abdomen exposed. A technician coats her belly with a jelly-like substance and then runs a scanner back and forth across her abdomen. The scanner

---

[8]A study reported during the height of the U.S. health care debates found that routine use of prenatal ultrasound screening does not significantly improve outcomes for low-risk women (Leary 1993). The study claimed to demonstrate that if screening were limited to high-risk women, or about 40% of all women, savings of $500 million could be achieved. One physician, Richard Berkowitz, was quoted as saying that if the test is not offered to all women, "physicians will have to be extremely vigilant in searching for the many problems or conditions that are indications for obtaining a scan" (Leary 1993:A16). In my own study, sonographer Donald Truitt addressed this issue: "Ultrasound shouldn't be a regular part of prenatal care. The patient should have a reason to have a sonogram, and there are lots of reasons. The only thing that isn't on the list of reasons to have sonography is a perfectly normal, healthy mother with a planned pregnancy, who knows when she got pregnant, and her size matches her dates, and there's nothing wrong with this person. They could have their babies completely on their own without any technological help of any type...So they don't need the sonogram. Right now, approximately 60-70% of these patients have one of the reasons to have a sonogram. The real question is, by adding the last 30-40%, how much do you really accomplish? And now we have a very good study which shows that you don't add that much."

bounces sound waves off of her "insides" and then transmits the images to an ultrasound monitor, which both displays and records the images. In fetal medicine, the ultrasound image does not "show" the mother but rather symbolically and visually excerpts and isolates the fetus from her body. In the domain of clinical decision making, these visual images of fetal bodies replace the material fetal beings still inside their mother's bodies in another part of the hospital or at home. The ultrasound representation *is* the phenomenon.

While actually doing an ultrasound may be fairly simple, learning to interpret sonographic images is often more difficult. It is a highly technical practice, and is itself the focus of a discrete medical specialty. Dr. Truitt told me, "Sonography is rife with poorly trained practitioners...It is difficult to learn, it's very difficult to learn. And, after training people after years to do this and how difficult I've found it to be, it never ceases to amaze me how many people in the world think that they can just find the on switch to do this job. Let me assure you, that simply isn't possible." That sonographic experts are a necessary component of the fetal surgery enterprise is illustrated in the many descriptions of fetal treatment programs which stress their interdisciplinary nature, noting sonography as a key element. It is also obvious from the ways in which other practitioners, such as fetal surgeons and obstetricians, discuss sonographers. For example, Walter Siegel, an obstetrician, remarked, "Dr. Truitt and I developed a very good working partnership. We were doing procedures in sonography...and from very early on, the concept was not always just diagnosis." These partners formed an ultrasonography group, which eventually, in the early 1980s, became an important part of the establishment of a fetal surgery team of specialists at Hilltop Hospital.

There is widespread consensus within fetal surgery that ultrasound has been instrumental in spurring the growth of the specialty. In responding to my questions about the origins of fetal surgery, including the lag between early efforts in the 1960s

and contemporary work, most informants cited ultrasound as a key factor. In other words, fetal surgery could not have progressed from where it was in the 1960s to the point where it is today without ultrasound. Lab technician Judith Lahey remarked enthusiastically that it was "definitely prenatal diagnosis, primarily ultrasound" which accounted for the development of fetal surgery. Dr. Truitt, the sonographer, stated, "Ultrasound is extremely important to fetal treatment programs. First of all, it's crucial to identify the fetus at risk to be certain that diagnosis is correct...We wouldn't even stick a needle into a uterus today without ultrasound guidance!" These informants point to changing conventions and standards of practice and suggest that fetal surgery could not have expanded in the 1960s prior to ultrasound's development. In short, without adequate diagnosis of structural defects, treatment was irrelevant. It was only with the introduction of ultrasound into fetal medicine that treatment for certain conditions became a viable possibility.

Rather than seeing these changes in a technologically determinist way, it is important to recognize that the use of ultrasound technology within fetal surgery and the development of the specialty occurred simultaneously and not necessarily sequentially. In other words, although ultrasound was a major actor in creating the field of fetal surgery, this new specialty in turn bolstered the use of ultrasound in reproductive medicine. Since the specialty's inception, clinicians have focused on sonographic images in making treatment decisions, eschewing more "traditional" forms of fetal diagnosis involving direct physical contact with a pregnant woman's body. For example, at fetal treatment meetings at one institution where clinicians discuss problematic cases, there are no pregnant patients in the room; all eyes focus on the ultrasound images which ostensibly represent the fetus in question.

In addition to prenatal diagnosis prior to surgery, ultrasound is also used *during* fetal surgery. As Dr. Truitt points out, "During the procedures, ultrasound is frequently used to monitor the fetus, to map the placenta, make judgments about

returning amniotic fluid volume, if necessary guiding transfusion of a fetus--all of these things are very crucial. Ultrasound will always be a major part of fetal treatment programs." Because of sonography's central role, sonographers are key participants in all phases of fetal surgery from diagnosis to follow-up. Fetal treatment meetings in which most practitioners participate to discuss cases are in effect run by sonographers, who present sonographic images of each case for discussion and review. This is quite different from historical work in the 1960s, when ultrasound was not yet a technical reality in medicine. During the earlier era, radiologists with expertise in x-rays were key members of fetal treatment teams.

In terms of how these practices connect to reproductive politics, it is important to consider how this technology affects the pregnant women who undergo surgery. Prenatal diagnosis may profoundly affect a woman's experience of pregnancy and of her fetus (Rothenberg and Thomson 1994). Following prenatal diagnosis, women are confronted with an often confusing array of "choices:" abort, carry a potentially defective baby to term, or opt for either non-surgical or surgical treatment. Depending on a woman's particular circumstances, including how entrenched she may already be in the health care system, ultrasound and other technologies may shape the choices she ultimately makes about her fetus. For example, Rothman (1986) has argued that amniocentesis transforms pregnancy into a "tentative" event, contingent on the outcome of testing. Pregnant women often do not allow themselves to define their fetuses as potential babies until they have been given what I call a *diagnostic seal of approval.* As Rapp (1990:41) has pointed out, "amniocentesis and other new reproductive technologies open a Pandora's box of powerful knowledge."

The impacts of diagnostic technologies such as ultrasound are not limited to the biomedical domains in which they are used. Often these images percolate into public consciousness via cultural channels, as discussed in Chapter 1. For example, ultrasound provides "snapshots" of a developing fetus for a pregnant woman; in this

sense it becomes a high-tech method of getting baby's first picture for the family album. This may have implications for women's decisions to seek treatment. Routinely seeing visual images of her developing fetus may contribute to a pregnant woman's decision to select intervention rather than abortion. Such images are also deployed by political groups intent on granting fetuses personhood in efforts to restrict abortion rights (Petchesky 1987; Rapp 1990). Anti-abortion groups display these images publicly, as in the propaganda film *The Silent Scream*, using their "erasure" of pregnant women to reframe the maternal-fetal relationship as one of opposition.[9] Ultrasound works in this sense because "the maternal space has, in effect, disappeared and what has emerged in its place is an environment that the fetus alone occupies" (Stabile 1992:180).

In sum, then, ultrasound has been a core element of fetal surgery, contributing to enhanced access to the fetal patient and to the development and growth of the specialty. While other prenatal diagnostic technologies have been significant in the emergence of fetal treatment generally, ultrasound holds a unique place in the diagnostic arsenal. Through providing visual data about a fetus' condition, this technology makes accessible information about anatomical defects. This links it specifically to experimental fetal surgery, which is oriented toward repair of structural defects. Because of this close interweaving of diagnosis and treatment, ultrasound has been a central component of work practices organized toward enhancing access to the fetal work object. Fetal surgery could not proceed until adequate sonographic assessments were done. Sonographers, expert in performing and interpreting sonograms, have been major actors in this domain since the introduction of ultrasound into fetal medicine. As situated within clinical practice, then, ultrasound is both a product and a constituent of this complex domain. While it may not be directly and

---

[9]A common saying among the anti-abortion ranks is that if pregnant women's abdomens were transparent, there would be no abortions. Such an anatomical feature would also likely make fetal diagnosis and treatment much easier.

causally responsible for the development of the field, it has certainly had a significant influence on the technical contours of fetal surgery.

Tails from the Lab: Animal Experimentation in Fetal Surgery

Like ultrasound and other prenatal diagnostic technologies, animals have also been instrumental in the emergence of fetal surgery. Within studies of science, technology, and medicine, a number of scholars have examined the use of animals in research practices. Clarke (1987), for example, analyzes the significance of animals as research materials in the development of the reproductive sciences. She describes the collection, preservation, and use of research animals as both constraining and facilitating scientific practice. Haraway (1989), in her eloquent archaeology of primatology, narrates Western peoples' fascination with non-human primates. She not only describes how "we" have symbolically projected cultural meanings onto primates, but she also illustrates the very real and material uses of primates in anthropological and other scientific research. Still others have investigated different aspects of animal research, such as how animals are transformed into scientific objects within laboratory research (Lynch 1988). All of these studies chronicle the almost mandatory use of animals as first-order experimental sites in the scientific research enterprise.

Biomedical research, in particular, has been conceived and built upon animal experimentation.[10] Indeed, it is a hallmark in the history of Western medicine that clinical practice in human patients can proceed only after animal tests have rendered new techniques and treatments "safe." In seeking to establish the legitimacy of experimental approaches, the number of animals tested is an important and oft-cited

---

[10]A recent report of the Tufts University Center for Animals and Public Policy announced that the number of animals used in research has declined by over 50% since 1968 (Hilts 1994). The report also noted that the amount of pain experienced by animals in research was understated by universities and overstated by animal rights activists. It cited a study from the Netherlands, the only country which has collected data on animal pain and distress caused by research, which showed that about one quarter of animals experienced severe discomfort, one quarter moderate discomfort, and about half minor discomfort. See also Rader (1995).

benchmark. Animal research in biomedicine includes not only dissection of dead animals, but vivisection in live animals including experimental surgical operations, administration of pharmaceuticals, wounding, and a range of other tests. Because of the nature of animal experimentation, it has long been controversial and the subject of intense ethical and political debate. It is not my intention here to elaborate upon these ethical issues.[11] Rather, I am interested in exploring the use of animals as technological work objects in experimental fetal surgery, focusing in particularly upon how animals have been conceptualized, accessed, and used, as well as how their use has contributed to the emergence of the specialty.

As discussed in Chapter 3, sheep and primates were key work objects in the history of experimental fetal surgery. Sheep, widely available in England and New Zealand, were used in early fetal physiology experiments as well as in subsequent basic research on fetal therapy. In New York and Puerto Rico, non-human primates, particularly Rhesus monkeys, were central to early experimental efforts. Adamsons told me that "biomedical application from sheep research was not sufficient," although he also "recognized and shared others' frustrations with primates." He described how primate models prepared in Oregon "deteriorated within ten days when brought to Cayo Santiago. We realized it was exposure to lights and the sounds of human activity. At Oregon, the animals were open, friendly, used to interacting with humans. The animals were treated well, like pets. At Puerto Rico, the primates had no human contact, and were kept in cages and hosed down. They really freaked out when placed in restraining chairs. So it turns out we couldn't do sustained observations in the Puerto Rico primates."

---

[11] I choose not to address these issues here because they are not directly relevant to the argument I am attempting to make about animals as work objects. This does not mean I do not have an ethical position on animal research in biomedicine. Indeed, in another paper I have explored at length the issue of human accountability to each other and to animals (Casper 1994). I believe it is incumbent upon each of us to seriously consider the ways in which we use other living creatures in our practices; perhaps the data presented here will provoke and inspire on all sides of the debate.

In addition to these "standard" research animals, Liley and Liggins also attempted to acquire four armadillos from a colleague in the U.S. The nine-banded armadillo was of interest to him because the animal usually has identical quadruplets, a property considered useful in experimental work on fetal nutrition, immunology, and endocrinology.[12] Liley's correspondence with his Texas contact and the New Zealand Department of Agriculture reveal the complicated nature of animal research. In addition to arranging for the armadillos' capture in Texas, Liley also had to coordinate their shipment to New Zealand, negotiate quarantine procedures, and care for them once they arrived. Because of New Zealand's relative isolation, rabies was non-existent and of considerable concern to animal health officials. These arrangements ultimately proved too burdensome, and Liley never got his Texas armadillos.[13]

Although contemporary fetal surgeons have not used armadillos in their work, they have extensively experimented on sheep, primates, rabbits, and other animals, building on earlier fetal research efforts of the 1960s. Dr. Hansen told me that "there were over 1,000, maybe even 2,000, experiments done on animals before anything was ever done on humans." Sheep are widely used in reproductive research for a variety of reasons. According to Judith Lahey, a laboratory coordinator at Hilltop Hospital, sheep are good because "they are large animals with relatively long gestations in which to see the effects in utero. Also, their uteri are very non-reactive, unlike

---

[12]When I asked Liggins why they wanted armadillos, he replied "Well, armadillos have certain charms in that they have identical quadruplets. Otherwise, they're not very attractive experimentally."

[13]On April 14, 1967, Liley wrote to the Director of the Animal Health Division in Wellington, New Zealand: "For some time we have been interested in the 9 banded armadillo of Texas as an experimental animal for work in fetal physiology...Some months ago I enquired of Mr. Wood, Director of Auckland Zoological Gardens about the possibility of obtaining and caring for armadillos...This American enthusiasm and generosity catches us on the wrong foot and I would therefore appreciate your advice as to whether these animals, presumably captured in the wilds, could be air freighted to New Zealand and quarantined here or whether quarantine is essential in a Zoo in the U.S." After receiving a reply from the animal health officer, on April 28, Liley wrote to J. Gregory Miller, his source in Texas: "I have now heard from the Director of Animal Health Division, Department of Agriculture, and unfortunately they will only permit importation of armadillos into New Zealand on a zoo to zoo basis. If these animals you have so kindly captured could be held in the Houston or some other registered zoo for the required 6 month quarantine period we would have no difficulty getting the necessary import permits, but if this is at all inconvenient for you to bother with I guess the simplest thing would be to let them go."

monkeys or humans." In other words, when an ovine uterus is opened surgically it generally does not go into labor, thus avoiding one of the most significant problems faced by fetal surgeons. On the other hand, because of this physiological quality, investigating fetal surgery in sheep provides little practical assistance in solving the preterm labor problem in humans.[14] Although sheep are perhaps not as ubiquitous in the U.S. as they are in New Zealand, they are, according to a lab coordinator, "very easy to get." Lahey's laboratory, for example, has a contract with a farmer in the northern part of the state. Based on research needs, the lab orders sheep to be bred at specific times. Pregnant sheep are then delivered to Hilltop Hospital where experimental surgery takes place.

Harrison (1991:280) provides a graphic description of how sheep are used as work objects in experimental fetal surgery. He begins by asserting that in order to study the pathophysiology of a particular type of structural defect and the possibility of surgical correction, "it was first *necessary* to develop an animal model" (emphasis added). This meant producing the structural defect (in this case a urethral obstruction) in fetal lambs and then attempting to correct it surgically. Harrison (1991:280) writes: "We produced an accurate model of severe bilateral hydronephrosis in the fetal lamb by ligating the urachus and occluding the urethra with an ameroid constrictor...Then we decompressed some of the obstructed fetuses by performing a suprapubic cystostomy at a second fetal operation about 3 weeks later and compared obstructed, decompressed, and control lambs at birth...To test whether obstruction earlier in fetal life leads to renal dysplasia, we produced complete unilateral ureteral obstruction in fetal lambs at the beginning of the second trimester." In other words, an obstruction was produced by tying off the urethra in an attempt to induce renal problems. As this passage indicates, before fetal surgery was tried in

[14]Fetal surgeon Karl Hansen told me, "The sheep, however, doesn't reflect the physiology of the disease very well because first, it's a completely different animal. But it's chosen as the fetal model because it does not have a contractile uterus that would tend to abort. So it was chosen as the model and that's where some of the techniques were perfected."

human patients in the early 1980s it was first systematically performed in sheep. As with most experimental biomedical research, animals provided the material basis for new knowledge about clinical practices.

Not only were sheep designated a "necessary" precursor to humans, they were also an early step in a successive hierarchy of research animals. As one researcher told me, "there is a progression of experimentation from sheep in the early stages of research to monkeys in the later stages, when techniques and procedures are almost ready for human application." Because non-human primates are most like us, they are the penultimate research objects, the final testing ground before human application. Physiologically, their bodies are similar enough to human bodies that experimental findings in non-human primates are considered especially valid and legitimate.[15] Their affinity to humans thus marks them as prime work objects in biomedical research, yet they are also highly placed along "our" moral continuum. Work on non-human primates may thus generate a great deal of controversy. As Haraway (1989:3) remarks, "Many people...have emotional, political, and professional stakes in the production and stabilization of knowledge about the order of primates." Thus, while their "like us" quality does not always protect non-human primates from the worst hazards of biomedical research, it may at least tweak our collective conscience and challenge our notions of moral accountability.

Despite these moral concerns, a recent volume illustrates the central and growing use of non-human primates as preferred animal models in reproductive research, a body of knowledge upon which much experimental fetal surgery is based (Brans and Kuehl 1988). Many of the volume's contributions attempt to demonstrate that non-human primates are "ideal" animal models because they are "closely

---

[15]Some researchers question how "faithfully" any animal model reproduces human experience. For example, Martin and Murata (1988:276) argue that "each species is unique, and sometimes surprising differences in physiology turn up between even fairly closely related species...One should not assume that the laboratory primate is a superior surrogate for experimental observations on the human fetus simply because they are closer to humans on the phylogenetic tree."

analogous" to humans (Flake, Harrison et al. 1988:245). Sheep and other animals are seen as "phylogenetically lower" and thus not useful in evaluating "the safety and feasibility of fetal intervention in humans" (Ibid.) Of major importance to any research practice involving animal models are techniques for transforming animals into appropriate work objects. Establishing chronic instrumentation of the fetus, or constructing a useful experimental work object which may be used across a specified period of time, is seen as a critical step (Murata, Fujisaki et al. 1988). For example, one important requirement is assuring that normal pregnancy can continue after a surgical procedure; this is most often accomplished through sustained observation and blood sampling. Other factors which must be considered in producing good primate models are: 1) preoperative care (transportation of the animals to the research site, observation of behavior); 2) preoperative fasting (withholding food prior to anesthesia); 3) prophylactic tocolysis (administering pharmaceuticals to prevent uterine activity); 4) prechairing (placing the animal in a restraining chair before surgery so that it may adjust);[16] and 5) appropriate techniques during the surgical procedure (Murata, Fujisaki et al. 1988).

As with sheep, constructing a useful primate model for fetal surgery means first producing fetal defects in the lab. Research animals, usually Rhesus monkeys, are selected as healthy to begin with; any lesions or defects for which surgical repair is attempted must be artificially induced prior to the experimental procedure. (This is discussed more fully in the section on wound healing below.) In order to "repair" these defects, researchers prep the monkeys with anesthesia and tocolysis. Surgery

---

[16]Chairing refers to the process by which primates are restrained during and after operative procedures. They are strapped into chair-like apparatuses and are unable to move about or use their arms and hands. The basic idea of chairing is to prevent the animal from disrupting the experiment by removing instruments, dislocating stitches, and so on. Because chairing seems to cause emotional distress in many animals, prechairing is used to acclimate the animal before surgery takes place. Murata, Fujisaki et al. (1988:233) state, "although prechairing for one day to ten days before the operation appeared to help individual monkeys to adjust themselves to the restraining chair more easily after the operation, retrospective statistical analysis failed to demonstrate significant effects of prechairing either on success rate or on duration of the preparations. Moreover Chez reported an increased incidence of spontaneous abortion in the animals that were prechaired in early gestation."

is performed in an effort to determine the feasibility of opening and re-sealing the uterus. The following provides some insight into how these experiments are done: "The pregnant monkey is premedicated with ketamine 10 mg/kg...[and] is positioned on the operating room table in a left lateral tilt...Anesthesia is induced and maintained...The gravid uterus is exposed through a midline incision and gently palpated to locate the two placental disks...Amniotic fluid is withdrawn through a syringe, kept warm, and returned when the uterus is closed...The appropriate fetal part is exteriorized and the planned operation performed...The uterus is closed with a TA-90 stapling device" (Flake, Harrison et al. 1988:246-7).

Monkeys used for research at Hilltop Hospital were obtained from a primate research center located at a nearby campus, where the procedures were also performed.[17] Like sheep, monkeys are "relatively easy to obtain" according to a laboratory worker. According to fetal surgeons (Flake, Harrison et al. 1988:246), conducting all experiments at one research center "greatly facilitated uniform care and allowed the experimental groups to be compared with normal control time-dated pregnancies under the same environmental conditions." The first 25 cases in one center were used to develop anesthetic and tocolytic regimens that would permit fetal surgery in human primates.[18] As the surgeons gained more experience through continued research, many elements in the original protocols were modified. In part, this is because "initial results in this difficult model were discouraging. However, results improved with modification in techniques and increasing experience over two years. We achieved the goal of being able to operate on fetal monkeys late during the second trimester and during the third trimester without significantly increasing maternal or fetal mortality compared to that of a nonoperated group" (Flake, Harrison

---

[17]The U.S. government has maintained a network of Regional Primate Research Centers since the 1920s, largely for biomedical research. Standardization of non-human primate materials has been a core focus, as has disease control. See Clarke (1987) and Haraway (1989).

[18]Flake et al. (1988:251) state, "The initial goal of our studies was to develop surgical, pharmacologic, and anesthetic techniques that could be successfully applied to fetal surgery in the human."

et al. 1988:251). The results reported by this team included intrauterine fetal deaths, abortions, and "significant maternal complications" including maternal deaths, uterine rupture, and decreased fertility (Flake, Harrison et al. 1988:260).

Despite these early discouraging reports, fetal surgeons continued experimental surgery on non-human primates in order to glean information that might prove useful when applied to humans. Although the knowledge produced by these experiments has been of mixed value in clinical practice, the very existence of the experiments is used as a legitimating strategy by fetal surgeons in "claimsmaking" (Aronson 1984) about their work. As one team (Flake, Harrison et al. 1988:260) states, "there is no substitute for experience and success with the nonhuman primate model." This credo is illustrated in the frontis to *The Unborn Patient*, where there appears a close-up color photograph of a fetal monkey being exposed during open surgery. It is also repeated in a video produced at Hilltop Hospital for viewing by potential patients; the audience, presumably pregnant women and their families, is assured that the technique of fetal surgery has been worked out in research on "hundreds of animals," including sheep and Rhesus monkeys. Further, in setting out criteria for undertaking fetal treatment, Harrison (1991:11) asserts that such interventions were not attempted at his institution until "the pathophysiology of the disease was studied in an appropriate animal model" and "the feasibility and safety of intervention was established in a rigorous model (i.e., the nonhuman primate)."

Animal research, especially in non-human primates, has also been used to legitimate funding for clinical trials. In a proposal to the National Institutes of Health, the Hilltop Hospital team wrote, "In the laboratory, we have developed models that accurately reproduce the clinical features of [congenital diaphragmatic hernia], including the excessive mortality of the untreated condition...With this early clinical experience based on thorough laboratory and clinical research, we stand at a crossroad for the further development of open fetal therapy. We believe that the next

logical step in the development of this modality requires the assessment of its efficacy in the form of a clinical trial." In sum, the body of unnatural experiments done on non-human primates, in which fetal surgeons produce the problems to solve, is used to buttress and justify their claims that fetal surgery is well-researched and efficacious. It is also used to support the enterprise of open fetal surgery through enhanced linkages to funding networks and referrals of patients. Ironically, animal research may also insulate fetal research from reproductive politics by avoiding, or at least postponing, extensive experimentation on human fetuses where abortion is politically salient.

In the next section I also explore animal research in a more specific way, focusing on fetal wound healing as an experimental paradigm which emerged from the clinical practice of open fetal surgery.

The Fetal Wound Healing Paradigm: A "Blueprint" From/For Clinical Practice

As discussed in Chapter 2, the material and symbolic nature of fetuses constrains their availability as work objects in scientific and biomedical research. Controversy surrounding the use of *living* fetuses as research objects has permeated scientific practice since the early years of fetal research and has resulted in numerous federal regulations delimiting such practices. In part, such controversy is due to the ambiguous, contested status of fetuses in utero and to the politics of reproduction which pervade American life. Experiments involving live fetuses raise critical questions about the meanings and boundaries of life and what it is to be human, and often deeply trouble interested publics. Yet, despite persistent controversy over the use of live fetuses in research, exceptions are often made if research is defined as therapeutic or beneficial for the fetus, as in experimental fetal surgery.

One such exception is fetal wound healing, which exemplifies the proliferation of technologies and research paradigms which have emerged from the "therapeutic"

practices of fetal surgery. Contrary to traditional expectations of the basic research/clinical practice relationship, in which clinical knowledge is believed to flow from experimental work, fetal wound healing is a "basic" research paradigm largely *derived from* "clinical" practice. The "discovery" of fetal wound healing processes was made possible by increased accessibility of fetuses via ultrasound and surgical technologies (Adzick and Longaker 1992a). For example, in the 1980s surgeons conducted in utero fetal therapy for a range of disorders, including congenital diaphragmatic hernia,[19] sacrococcygeal teratoma,[20] chylothorax,[21] congenital hydronephrosis,[22] congenital heart disease, cystic adenomatoid malformations,[23] and craniofacial defects. From these quite diverse surgical experiences, "the observation was made...that the fetus appears to heal without scar formation" (Adzick and Harrison 1992:2). Until scientists actually opened a pregnant woman's body, removed her fetus, operated on it, and returned it to her womb for subsequent development and delivery, there was little if any recognition that fetal wound healing might differ from adult healing processes.

Unlike adult wound healing, in which tissue repair involves a series of biochemical processes that ends in scar formation, fetal wound healing is scarless. Adult wound healing is generally classified as a series of specific events, including wounding, inflammation, cell proliferation, and formation of fibrous tissue. Fetal

---

[19]Congenital diaphragmatic hernia (CDH) is a condition in which there is a hole in the diaphragm, causing fetal organs to migrate upward into the chest and impairing lung development. Many fetuses with CDH die at birth; those who live and undergo pediatric surgery after birth generally have respiratory and other problems for the rest of their lives. Fetal surgery for CDH is designed to repair the diaphragm in utero and reposition the organs in the fetal abdominal cavity, thereby making room for subsequent lung development.

[20]Sacrococcygeal teratoma refers to a tumor located on both the sacrum, or the part of the vertebrae directly connected to the pelvis, and the coccyx, or the end of the spinal column.

[21]Chylothorax is a condition in which there is an accumulation of milky fluid in the pleura, or the serous membrane enveloping the lungs, and lining the walls of the pleural cavity. It usually causes severe respiratory problems.

[22]Hydronephrosis refers to an excess build-up of fluid in the kidneys caused by an obstruction to the flow of urine; untreated, it generally results in renal failure and death.

[23]Cystic adenomatoid malformations refer to tumors in the connective tissue surrounding the urinary bladder or gallbladder. Like hydronephrosis, this condition can cause severe kidney damage and/or renal failure.

wound healing occurs without inflammation or formation of fibrous tissue, thus making fetal wound healing more akin to *regeneration* than to the healing scarring process in adults. Indeed, the younger the fetal patient is at the time of surgery, the more likely it is to regenerate and to be born without scars. As one pediatric surgeon remarked about the fetal surgery experience at his institution, "the only way we could find the incisions on some of these babies was because the stitches were still in place" (quoted in Skerrett 1991).

There are several factors which may account for the immense differences between fetal and adult wound healing. Importantly, fetuses, unlike adults, exist in the sterile, thermally controlled confines of the womb and are bathed continuously in amniotic fluid. They also grow at a phenomenal rate: "cellular turnover and differentiation are so rapid in the normal fetus that the adult process of stimulating and recruiting normally quiescent fibroblasts may not be necessary in the fetus" (Krummel and Longaker 1991:527). In addition, hyaluronic acid (HA), an essential component of both adult and fetal wound healing processes that promotes cell growth, is produced and sustained in fetal wound healing at much higher rates. "A prolonged presence of HA in fetal wounds may provide the matrix signal orchestrating healing by regeneration rather than by scarring" (Adzick and Longaker 1992a:60). Although the precise physiological basis of fetal wound healing remains unestablished, there is widespread scientific agreement that it differs from adult processes in terms of cells, environment, or a combination of the two, as described.

As with fetal physiological research, constraints on practice resulting from controversy about fetal research have led scientists to investigate two major alternatives to human fetal work objects: animal models and, to a lesser extent, in vitro models. In addition to human fetuses, fetal wound healing research has been carried out on chick embryos, opossums, guinea pigs, mice, rats, rabbits, sheep, and non-human primates (Krummel and Longaker 1991; Adzick 1992). Despite a short

gestation, the rabbit is the most widely used animal model, while non-human primates are considered the most rigorous in terms of applicability to human fetuses as discussed previously. However, "the fetal monkey model has the drawbacks of high expense and the need for postoperative monitoring and tocolysis to prevent preterm labor" (Adzick 1992:79).[24] In all animal models, wounds and lesions are simulated and examined by researchers using assay systems, subcutaneously implanted wire mesh cylinders, and other "wounding" technologies.

In vitro models are used to study the effects of local biochemical factors on fetal wound healing. In this type of research, wounded tissue is removed and isolated from the rest of the organism and maintained in laboratory conditions using cultural media.[25] Scientists investigate the role of circulating cells which migrate to the wound site and are incorporated into the wound healing process. One example of the in vitro technique is the fibroblast scratch model, in which scratches are made on a layer of human neonatal skin. Fetal and postnatal calf serum are then applied to the wounded tissue and studied for significant effects and differences. The purpose of the model is "to determine if fetal serum contains unique components that stimulate the process of wound healing in a fetal-like manner" (Burd, Longaker et al. 1992:257). Another example of in vitro technology is the sheep explant model, in which pieces of fetal sheep skin are placed on gauze in culture dishes and combined with different substances. Different combinations of fetal sheep skin and growth factors are then analyzed for effects. Both models permit manipulation of fetal wound healing "in a controlled fashion," allowing scientists to "elucidate some of the individual

---

[24]Tocolysis refers to the use of drugs called tocolytics to prevent and/or arrest uterine contractions. A major problem in experimental fetal surgery is premature onset of labor. With respect to animal experimentation, sheep, unlike primates, are claimed to have very non-reactive uteri, which make them useful models for fetal surgery research. However, because of this property sheep are seen as being of limited comparability to humans.

[25]Scientific language often raises interesting questions about distinctions between nature and culture, technical and social. As Busch (1991:113) argues with respect to the cultural medium of the petri dish, "the form that culture takes will reveal something about both the cells in the dish and us, for in the final analysis there is no way to separate our cultural evolution from theirs."

components that participate in the phenomenal process of scarless fetal skin repair" (Burd, Longaker et al. 1992:262-63).

Fetal wound healing research is assiduously pursued by scientists because it is construed as having immense therapeutic potential. Indeed, fetal wound healing is often referred to as the "blueprint" for ideal tissue repair (Adzick and Longaker 1992a). Examples of claimed potential therapeutic benefits of this knowledge include application to adult tissue repair (e.g., enhanced wound healing, control of wound contraction, development of antibodies) and to surgical correction of structural deformities such as fetal cleft lip.[26] Scientists believe that it is "the ultimate 'pie in the sky' to apply what is learned from fetal wound healing to the world outside the womb" (Skerrett 1991:1066). Consider the following illustration of scientists' hopes for downstream application of this research: "Fetal wound healing represents a paradigm of ideal tissue repair that we would like to emulate in children and adults. As scarring and fibrosis dominate some diseases in every area of medicine, an understanding of fetal wound healing should help develop therapeutic strategies to avert the devastating consequences of excessive scar formation" (Adzick and Longaker 1992b).[27]

Scientists' claims about the potential therapeutic benefits of fetal wound healing are more congruent with the view that basic research leads to clinical applications, rather than the other way around. This perspective is common in fetal research and treatment domains. For example, when asked whether fetal surgical practices have contributed to basic physiological research, fetal physiologist Joseph

---

[26]It is not difficult to imagine that fetal wound healing might be of great interest to the cosmetics industry and plastic surgeons.

[27]Given the scope of scarring and fibrosis in medicine, it is possible that fetal wound healing researchers would find many supporters within medicine for their work. For example, plastic surgeries, transplantation, amputations, prosthetics, and other areas would likely be transformed by fetal wound healing applications, suggesting multiple possibilities for enrollment of allies, a key element in the formation of stable scientific and technological endeavors (Latour 1987). On the other hand, fetal wound healing knowledge could provide yet another lever with which fetal surgeons attempt to gain control over other medical specialties; see Chapter 5.

Sigler replied, "I don't really think so. I think most of it has been a one-way street." Yet, as the fetal wound healing paradigm illustrates, the basic research/clinical application relationship may be more of a two-way street than scientists and clinicians are willing or able to acknowledge. As described, the impetus for fetal wound healing research was the emergence of the fetal work object via surgical practices. Constraints on the use of live human fetuses in wound healing research precipitated the development of animal and in vitro models, somewhat obscuring the clinical origins of such research.

In sum, fetal wound healing research illustrates the diversity of practices located within the domain of experimental fetal surgery. Although clinical practice is often built upon physiological and other basic research in the laboratory, working on patients within the operating room may lead to scientific "discoveries." Clinical researchers must then move from the operating room back into the laboratory to seek answers to these new questions. Because fetal wound healing research emerged within the context of experimental fetal surgery, it was from the outset cloaked in a certain legitimacy by its association with therapeutic research. By linking basic wound healing research to the downstream benefits of surgical experimentation, clinical researchers are able to pursue both sets of practices with some immunity from regulation and political controversy. Where fetal physiology legitimated as a basis for fetal surgery, fetal wound healing legitimates by offering "proof" of fetal surgery's scientific payoffs. Further, rather than being unidirectionally linked from research to treatment, the fetal wound healing paradigm embodies the hybrid nature of clinical practices. There is rather a continuum of both research and treatment activities located within the domain of experimental fetal surgery, with considerable overlap between different types of work. As with physiology, ultrasound, and animal research, the fetal wound healing paradigm is indicative of the heterogeneity of contemporary clinical practices focused on and organized around the fetal work object.

Conclusions

In this chapter, I have focused on the hybrid nature of clinical practice, using the examples of fetal physiology, ultrasound technology, animal research, and fetal wound healing research to illustrate my points. I have argued that medicine is not a singular entity; rather, it is a complex and contingent set of different but related scientific, technological, and clinical practices. In experimental fetal surgery, each of the four examples that I discussed has shaped the specialty. Each has done so, in its own way, by facilitating access to the human fetal work object. Fetal physiology has provided scientific knowledge about developing fetuses which surgeons use both to accomplish and to legitimate their clinical work. Ultrasound technology has offered visual access to fetal work objects, making available information about structural defects amenable to surgical repair and assisting during repair itself. Extensive experimental animal research has resulted in a body of knowledge about fetal diseases and their treatments upon which fetal surgeons base clinical decisions regarding human patients. With the expert interpretive assistance of physiologists, sonographers, and others, fetal surgeons have relied upon these data in making treatment decisions. Last, fetal wound healing has emerged from the clinical practice of fetal surgery as a new research paradigm, providing fetal surgeons with knowledge about how fetuses heal in utero. All of these practices are linked within the domain of experimental fetal surgery through the organization of medical work.

Thus, the clinical specialty of fetal surgery is shaped by a diversity of scientific, technical, and clinical work practices which can be and usually are made to feed into each other by enterprising actors. While it may be conceptually easier to classify these different activities as *either* science *or* technology *or* medicine, their imbrication in concrete work settings illustrates their hybrid nature. In this framing, what is significant about these types of practices is their dynamic quality, illustrating that

hybridization is a social process. Different actors are moving back and forth, to and fro, in and out of the divergent practices discussed here, with the overall goal of building fetal surgery into a successful enterprise.

Yet, although fetal surgery is hybrid in nature, it is not necessarily a seamless web of practices. In order for experimental fetal surgery to work, its practitioners must bring together an array of knowledges, techniques, tools, bodies, and practices. A great deal of work is often required to marshal different elements used to accomplish different aspects of fetal surgery. Strauss (1988; 1993) has called this type of work "articulation work" and Star (1986) has labeled it "triangulation." Berg (1995:140) phrases it slightly differently: "All these practices intermesh...The thoroughly heterogeneous practices are disciplined through equally heterogeneous means...getting and keeping a niche in place implies much *work*." A good example of this is the role of physiologists in conveying knowledge about fetal development to fetal surgeons or the role of sonographers in performing and interpreting ultrasound images used in treatment decisions. There is also the work required to coordinate the human, technical, and conceptual traffic between the operating room and the laboratory.

By focusing on process of hybridization in this way, some of the reproductive politics in experimental fetal surgery are brought into sharper view. Located at the interstices between different practices, as well as in the practices themselves, are a number of cultural tensions and contradictions. Between physiology and surgery, between animals and humans, between surgeons and their work objects, and between the laboratory and the operating room are spaces where much coordinating work must take place. Controversy surrounding fetal research imbues experimental fetal surgery and related practices with a spirit of illegitimacy. Clinical researchers must seek ways to legitimate their work, for example through fetal physiology or animal experimentation. Focusing on the ways in which they attempt to do this provides

insight into the political nature of experimental fetal surgery as well as surgeons' efforts to depoliticize their work. Thus, not only is fetal surgery an ideal site for investigating the hybrid nature of clinical practices, but it is also rife with politics: reproductive politics, professional politics, anti-vivisectionist politics, federal research politics, and so on. These politics are consequential for experimental fetal surgery because they impinge upon how work is done, particularly how access to fetal work objects is sought and obtained.

In sum, fetal surgery is a hybrid practice on many fronts and includes both clinical and political dimensions. This dynamic diversity forms the core of Chapter 5, in which I explore the contested nature of this type of work within a particular institutional setting, Hilltop Hospital.

Chapter 5

WORKING ON AND AROUND HUMAN FETUSES: THE HETEROGENEOUS DOMAIN OF CONTEMPORARY FETAL SURGERY

"The collective *structure of medical experience, the* collective *character of the hospital field--the clinic is located at the meeting point of the two totalities."*
(Foucault 1973)

"A special problem arises with interventional fetal procedures, especially those that require the expertise of specialists from very different fields...Because no single specialty training provides the total spectrum of skills and experience, this is an area in which 'turf' battles between medical specialties and 'ego' battles among team members may sabotage the fetal treatment enterprise. It is also an area in which cooperative efforts and teamwork can be productive."
(Harrison 1991a:9)

At its core, sociology is about "doing things together" (Becker 1986), how groups of people collectively weave and maintain the fabric of social life. Just as society itself is a collective enterprise, so too are its many institutional and cultural components such as medicine and science. Biomedical and scientific work are not only collective but also heterogeneous, as explored in the rich vein within medical sociology which examines the manifold contributions of medical work. Different sets of people with diverse skills, resources, and power do things together within particular institutional contexts, such as hospitals and laboratories. They use a variety of technologies in their work and draw on a wide range of general and specialized knowledges. The objects and goals of their work may be quite diverse, and the cultural meanings they attach to their work may also vary considerably. In short, biomedicine in the U.S. in the late twentieth century is heterogeneous along many dimensions. This has important implications for medical work and how it unfolds in concrete settings.

Fetal surgery is characteristic of other nascent medical specialties where diversity and heterogeneity are omnipresent. Contemporary fetal surgery, like the historical work in the 1960s, requires the participation of a broad array of medical workers and technologies. It is an enormously complex undertaking, in part because fetuses, located inside pregnant female bodies, are notoriously difficult to access. Finding and operating on the fetal patient and attempting to safeguard maternal health during these precedures requires multiple skills and tools.[1] There is a clear and necessary division of labor which forms the institutional contours of this new specialty and is constantly reinforced through professional interaction. Yet fetal surgery is complex for other reasons, as well. Because it is an emergent specialty, currently in what Bucher (1988) calls the "consolidation phase" of formation, its territory is not yet defined and staked out. Of the many different medical specialties involved in fetal surgery today, which set of workers will ultimately control fetal surgery remains to be established. Consequently, there is continual jockeying for position among the various groups in this domain.

In this chapter, then, I focus on fetal surgery as a heterogeneous domain, an intersection of multiple practitioners with different skills and interests. I argue that an organizational form characterized by diversity and all of the interactions it produces shapes what contemporary fetal surgery looks like in practice. Yet the most significant interactions, as the prefatory quote illustrates, are but two sides of the same coin: *cooperation*, which makes the achievement of fetal surgery possible, and *conflict*, which threatens this achievement at every turn. Participants are well aware of their need to cooperate with each other to make the fetal surgery enterprise successful even while they may disagree vociferously about exactly how to accomplish

---

[1]Harrison (1991a:9) states that "the fetus with an anomaly requires the attention of a team of specialists working together...Whether the patient is inside or outside the womb, its care is a continuum that requires the expertise of physicians trained in the care of mothers and babies. It is hard to imagine how one specialist, no matter how broadly trained, could take sole responsibility for the treatment of a fetus with a complex malformation."

this. This chapter explores several key aspects of the interactional nature of fetal surgery, focusing both on the "cooperative nature" and on the "turf battles" that Harrison (1991a) describes. Throughout, I attend closely to the implications of these differences for the health and well-being of pregnant women and their fetuses, for work practices, for the medical practitioners involved, and for the emergent enterprise of fetal surgery.

More specifically, this chapter draws on interview and ethnographic data from the Fetal Treatment Unit (FTU) at Hilltop Hospital. I first present several vignettes illustrating the dynamic complexity of fetal surgery. I next address the critical role of cooperation in creating and attempting to consolidate this new specialty. From its interdisciplinary roots in the 1960s, fetal surgery has continued to represent and enroll numerous different specialties. Like Liley, Adamsons, Freda, and their many colleagues, the degree to which contemporary participants believe they cooperate well with each other is a source of pride and a foundation for claims of legitimacy. Current providers recognize that cooperation is necessary in order to bring to bear on fetal problems all of their different experiences and skills. Yet this very diversity threatens to undermine the collective goal of cooperation. I next focus on three salient cleavages in fetal surgery along which participants diverge, often reflecting specialty boundaries. These include different definitions of work objects, different criteria for patient selection, and different views of a disease and its treatment. I conclude with a discussion of some of the more significant implications of these differences in terms of women's health and a return to key theoretical issues.

Theoretically, this chapter draws on two key interactionist concepts, the first of which is Mead's (1934) notion of *social objects*. (I discussed this concept at length in Chapter 2 and thus do not elaborate upon it here.) The second concept is *negotiated order*, originally developed by Strauss and his colleagues (1964:176) to characterize structure and social order as artifacts of interaction. Based on research in a

psychiatric hospital, Strauss et al. (1964) argued that the structured life of the institution is constituted by "continual negotiative activity." Negotiations may be patterned, as for example within a web of institutional relationships, but must be continually reconstituted as the basis for social order. Negotiations (and orders) are conceptualized as emergent, contingent, constrained, and fluid--hallmarks of interactionist approaches. Strauss et al. argue that these negotiations are integral to the coordination of work: the shapes of wards, clinical and administrative arrangements, and institutional rules are all products of negotiation.

In subsequent research, Strauss (1978; Strauss, Fagerhaugh et al. 1985) elaborated the concept of negotiated order in different ways, both by broadening the definition to include different dimensions of social order and types of negotiations, such as those constrained by coercion, as well as by linking negotiated orders to work activities more explicitly. More recently, Strauss (1993), building upon his earlier concept, proposed *processual ordering* to reflect that negotiation is but one type of ordering process. Strauss (1993:253-54) writes, "A quick review of the original usage of [negotiated order] will show that it referred to the overall order of mental hospitals, and perhaps of most hospitals in general...My use of a verb--ordering--instead of the usual noun is meant to emphasize the creative or constructive aspect of interaction, the "working at" and "working out of" ordering in the face of inevitable contingencies, small and large...Yet this leaves unanswered the question of the relationships between this new concept (processual ordering) and the older one (negotiated order). It is still my belief that though negotiation is only one of the interactional processes, it must be a major contributor to any social ordering." Although Strauss' newer concept is quite provocative, I use negotiated order in this chapter because it resonates more clearly with my data. I am interested in particular types of interactions, namely those centered on negotiation of differences, which seem especially germane to fetal surgery.

Both the concepts *social object* and *negotiated order* are important for my purposes here. The distinctive theoretical contribution of this chapter is in linking these concepts together to show how negotiations occur around particular work objects in the shaping of a new specialty. I conceptually situate fetuses within the domain of experimental fetal surgery by defining them as *work objects*, or material entities around which actors in this domain construct meanings and organize their work practices. Unlike many "routine" medical practices, fetal surgery is emergent, experimental, and focused on a particularly contested object in American culture and biomedicine, namely the human fetus. As such, fetal surgery is necessarily a product of intensive cooperation among practitioners with different skills, backgrounds, and perspectives. Yet it is precisely this practical organizational "requirement" that serves as a major basis of conflict within the domain of fetal surgery. Heterogeneity along a number of dimensions often leads to friction, ensuring that "cooperation" is possible only through continuous *negotiation* at different levels. The shape of fetal surgery is, in an interactionist sense, a processual order.

Some Vignettes from Fetal Surgery

What constitutes the shape of fetal surgery? The descriptions of fetal surgery which have appeared in this dissertation thus far illustrate graphically how different specialists come together to operate on fetuses. Yet the work involved in creating the unborn patient occurs both inside and outside the operating room, through meetings, consultations, telephone calls, conferences, and other interactional sites. In what follows I present several vignettes of fetal surgery as it occurs *outside* the operating room. Each of these narratives, taken from my fieldnotes, embodies important negotiative elements in the making of the unborn patient and opens a window onto what fetal surgery looks like in practice. As we shall see, diversity is foregrounded in these vignettes as multiple voices representing different specialties are heard

together evaluating cases and making treatment decisions. These vignettes provide a colorful backdrop for the analysis in the next section.

In the first example, providers discuss some key issues around maternal managment and the need for better monitoring:

> Dr. Sigler remarked that the major issue in monitoring is umbilical blood flow reduction. Sonya Delgado, an operating room nurse, commented that the fetal team might think about "getting information from other operations and techniques in obstetrics and gynecology." Albert Woo, an anesthesiologist, responded that a major difference between fetal surgery and other obstetrical/gynecological operations is the size of the uterine incision. There was wide agreement among participants that fetal surgery is indeed different. Dr. Sigler commented that "you can't decide what to do at the bedside as the fetus is constricted unless you know the cause." He also remarked that indomethacin should be avoided if possible. Harry Sartori, a cardiologist, suggested that echocardiographic monitoring of the umbilical cord might be "the best bet." Dr. Sigler again took the floor and cautioned that "you should be careful about throwing things into the fetus without knowing what's going on." Tracy Knox commented that "the patient contracted all day long pre-operatively" and asked for suggestions on how to inhibit contraction without dangerous medications. All of a sudden, a number of people were talking all at once about fluid, very little of which I caught. Sartori was suggesting a number of options to Graham, while Sigler was discussing fetal physiology for whoever was listening. Somebody remarked that procedures on

> the fetus were "insults." As the room quieted down, somebody wanted to know how the fetal team controlled for fluid loss. Graham responded that "the kid's never fully outside; we bathe him with warm saline constantly." Stan Cartwright, a neonatologist, remarked that "you can't compare normal labor with a woman who's had her uterus cut open and the fetus has its chest open." Sonya Delgado pointed out that morphine is often used post-operatively in ob/gyn surgeries where the fetus is removed (e.g., c-sections), but that "moms get to push the buttons." She suggested that self-selected morphine may not be suitable where a fetus remains in the patient.

The next vignette also highlights heterogeneity, although this time in the context of an unsuccessful surgery with which participants are attempting to come to terms:

> Dr. Siegel briefly discussed the case in terms of major advances in surgical techniques up until the present. He stated that there are many changes over what was happening just six months ago. New techniques worked out on sheep models were used in last week's case, such that the "fetus never budged." It was the "least reactive fetus to having its chest open" than any they have operated on to date. Surgeons spent one hour and five minutes on the fetus alone (nobody mentioned how long they spent on Debbie, the pregnant woman), and thought that premature labor would be a serious concern. There was tightening of the uterus during closing, at which time an anesthesiologist, Dr. Woo, gave the woman terbutaline. Siegel and Simmons, both describing the fetus' condition, remarked that it was normal for most of the day and into the night following

> surgery. It was given an echo, which was normal. Later that night, another echo showed tricuspid regurgitation. Harry Sartori, the attending cardiologist (not present at this meeting), looked at the echo and didn't think it was too abnormal. But he did see retarded umbilical flow and indications of placental resistance. The fetus subsequently developed heart problems and died. Siegel stated that "Dr. Graham opened the baby" and found that the liver was huge; in Tracy Knox' words, "the size of an orange." The liver was also found to be away from the ductus. At 2:28 p.m., Graham entered the meeting room in scrubs. Siegel brought him up to date on the discussion. When Siegel finished, Graham added that indomethacin had been administered. He also said that there were many possible explanations for what had gone wrong with the case.

The final narrative is characterized by the dynamic nature of collective evaluation of different cases which are reviewed during fetal treatment meetings:

> Siegel announced the second case as a 30-year old woman carrying a fetus with a large echogenic mass or lesion. Graham remarked that this case was "certainly on the bad end of the spectrum." Discussion ensued about the effects of post-operative analgesic on the fetus, which Tony Murphy referred to as a "black box." He stated, "It is very frustrating to do your best work and then lose the baby post-op. It makes one wonder if it's okay to put the baby back in and assume that mom will take care of things." Simmons suggested that sonograms be done post-operatively to avoid unnecessary fetal deaths. Graham remarked that functional assessment after birth is not

> very advanced: "short of blood tests, other factors (e.g., lung function) can't be measured very well." He commented that it would be "fun" to test the urine of the fetus to try to find the bladder.

Below, I analyze these and similar interactions within a framework which attempts to account for both cooperation and conflict in fetal surgery. I turn first to the significance of cooperation in this domain.

"A Spirit of Cooperation": Working Together in a Fetal Treatment Unit

While cooperation may be a necessary building block for "doing things together" in fetal surgery, it is by no means a naturally occurring phenomenon. Rather, cooperation, like all human interactions, must be achieved. The production of fetal surgery as a cooperative enterprise is characterized by numerous institutional activities, such as regular staff meetings designed to enable participants in this domain to work together. However, cooperation is not only the means to achieve certain ends, such as a healthy fetus, but may also be seen as an end in itself to satisfy certain institutional requirements related to fetal surgery. For example, in attempting to secure funding for experimental surgery or the approval of institutional review boards, it is more expedient for fetal surgeons to portray the fetal surgery enterprise as cooperative rather than as riddled with conflict. What follows is an elaboration of the cooperative components of the interactional scaffolding which make this nascent specialty possible.

The Fetal Treatment Unit I studied started at Hilltop Hospital in the early 1980s when a pediatric surgeon, a sonographer, and an obstetrician began working together on experimental fetal surgery.[2] Prior to the emergence of this work, these

[2]Although the extent to which the data presented here are generalizable to fetal surgery more broadly is questionable (see Appendix A), throughout this chapter I discuss the Fetal Treatment Unit and the broader fetal surgery enterprise as somewhat interchangeable. In part, this is because Hilltop Hospital is the premier fetal treatment institution internationally. As one fetal surgeon pointed out, "The [Fetal

physicians had often attempted unsuccessfully to save newborns whose diseases were too advanced for treatment. Their dismay at not being able to save afflicted neonates, coupled with the important historical precedents in fetal treatment discussed in Chapter 3, prompted the three colleagues to consider operating on fetuses *prenatally* in order to repair defects before birth or to prevent life-threatening conditions from developing at birth. As Harrison (1991a:8) states, "Pediatric surgeons and neonatologists were frustrated by caring for newborn babies with problems that were discovered 'too late to correct'...Thus, clinical frustration in dealing with uncorrectable neonatal diseases led to the experimental studies in which a model of the human disease was created in animals to study the pathophysiology of the process, to test whether the damage seen at birth was reversible if corrected before birth, and to establish the feasibility and safety of in-utero intervention."

In many respects, what these doctors hoped to accomplish was essentially what Liley, Adamsons, Freda, Asensio, and others attempted in the 1960s. Yet as innovative as the earlier work was, fetal surgery as it is currently practiced became a possibility only with the advent of sophisticated prenatal diagnostic technologies. Key among these was ultrasound which is capable of visualizing structural defects in fetal organs amenable to subsequent treatment. Important to the collective nature of this work, such technological developments required the input of a sonographic team for experimental fetal surgery. Neither fetal surgeons nor obstetricians (with some exceptions) are expert in performing or interpreting sonograms. Nor, as discussed in Chapter 4, did pediatric surgeons have much understanding of maternal health and the physiological intricacies of pregnancy, thus rendering it crucial that obstetricians be involved in the early phases of the program.

In terms of facilitating cooperation, it is significant that sonographers and obstetricians at Hilltop Hospital had already been treating fetuses *non-surgically* for

---

Treatment Unit] evolved through the interaction of professionals in many disciplines who share an interest in the fetus. As such, it is a microcosm of the fetal treatment enterprise throughout the world."

many years, beginning with intraperitoneal transfusions for Rh incompatibility based on Liley's work in the 1960s.[3] Open fetal surgery was deemed necessary at this center only when a fetal catheter inserted non-surgically to treat a blocked urinary tract refused to stay in place; replacing the catheter required surgically opening a pregnant woman's abdomen to access her fetus. Once a new catheter was developed it proved to be less recalcitrant than the old model, rendering open surgery unnecessary for this condition.[4] By that time, however, the door to fetal surgery had itself been re-opened and contemporary physicians had begun to consider applying this "new" technique to other diseases and conditions. Thus, a combination of technological innovation, professional goals, and institutional conditions resulted in renewed interest in open fetal surgery two decades after Liley's pioneering efforts in fetal treatment.

Like the clinical work settings of the 1960s in Auckland, New Zealand and San Juan, Puerto Rico, the Fetal Treatment Unit at Hilltop Hospital has been multidisciplinary since its inception in the early 1980s. The feasibility of experimental fetal surgery and the likelihood that it will become a routine medical practice are seen by participants as resting on cooperative interaction among its diverse practitioners. According to some participants (Howell, Adzick et al. 1993:143; emphasis added), "the institutional setting, organization, and *coordination* of the [FTU] are elements critical to its success." From the initial triad of pediatric surgeon, sonographer, and obstetrician, the fetal surgery team at Hilltop has grown to include a range of practitioners with diverse skills, perspectives, and backgrounds. These include perinatologists skilled in fetal diagnosis, fetal blood sampling, and intrauterine

---

[3]Liley's work may well have affected obstetrics as profoundly as it did fetal medicine. Shadbolt (1976) wrote, "Until Bill Liley literally breached the womb, the still young branch of medicine called obstetrics concerned itself mostly with the mechanics of delivery, 'the pulling and pushing and cutting,' as he dryly styles it, of the birth process itself. Knowledge of the unborn child came largely from zoological examination of dead fetal tissue. For long the unborn had been thought of as some blind and dumb plant or unconscious tadpole, static in habit, growing only in size. It is one of the century's many ironies that man had begun to know space before Bill Liley left so old a myth for dead."

[4]The new technology was called a Rocket catheter and is still used widely in fetal treatment practices.

transfusion; neonatologists, who must often intensively manage newborns after birth and during subsequent postnatal treatment; social workers who address psychosocial (including emotional, financial, employment, and social support) issues faced by pregnant women, their partners, and families; pediatric and obstetric anesthesiologists; nurses representing different specialties; geneticists; medical ethicists; and fetal physiologists knowledgeable in basic fetal biology. A successful fetal treatment center is, according to a prominent fetal surgeon (Harrison 1991a:11), a "blend of skills and expertise."

Practitioners within this domain are acutely aware of the diversity of requisite skills and knowledges. In addition to its attention in the published literature, every informant I spoke with talked at length about the necessity for cooperation and working together. Fetal surgeon Tony Murphy remarked, "It has to be a team approach...The team approach is key." Another surgeon, Jack Nelson, stated, "This is the most complex undertaking in surgery...We've got to enlist the aid of every person who's involved in every stage of this." Obstetrician Walter Siegel, speaking at a professional meeting, stressed that "it's important to have a well-rounded unit for fetal surgery, including neonatologists, pediatric surgeons, and so on." Sonographer Donald Truitt agreed that there is a great degree of cooperation and remarked that, "Considering some of the problems we've had, generally I would say it's a reasonably orderly group of people." And a social worker, Barbara Greenwood, remarked, "I think the days of territorialism are long gone...Because there's so much to be done for these families, everybody sort of pitches in. And I think there is a spirit of cooperation on this team that makes it reasonable to work on."

The significance of the "team" metaphor to describe working arrangements in the Fetal Treatment Unit cannot be overstated. According to practitioners, a number of general principles have evolved since the inception of contemporary fetal surgery to guide its development. Chief among these is that "fetal surgery is a team effort

requiring varying amounts of input from all team members" (Harrison 1991a:9). As well as specifying all the requisite members of the team (e.g., obstetrician, perinatologist, geneticist, surgeon, etc.), these principles also lay out additional rules underlying the organization of fetal surgery. For example, "although all members of the team can contribute to any particular procedure, there must be a team leader" (Harrison 1991a:9). Who is selected as team leader may be a source of conflict and cause for negotiation, despite the rule that "the procedure is done by the team member who is most likely to produce the best outcome" (Ibid.). Further, just as experimental fetal surgery is a proving ground for developing and implementing new procedures, it also provides "an invaluable opportunity to work out...the professional relationships that will enable the team to function smoothly. The lines of responsibility must be drawn clearly among team members before the choice of doing a procedure is offered to a patient" (Ibid.).

Certain organizational conventions within the FTU also indicate that cooperative teamwork is extremely important. At ongoing fetal treatment group meetings, a range of practitioners come together to discuss specific cases and strategies for treatment, evaluating past activities as well as planning for the future. Also, regular "consensus meetings" are held among clinicians and researchers to discuss current basic scientific research as it relates to clinical practices. It is here that new fetal technologies, developed in a fetal treatment lab using animal models, are first introduced into a clinical setting. In addition, fetal surgeons, obstetricians, genetics counselors, and social workers routinely meet with potential patients, often coordinating their schedules and agendas to coincide with a family's visit to the hospital. Further, there are ad hoc meetings on particular issues, such as a discussion of fetal and maternal management which took place following a rash of post-operative maternal health problems and fetal deaths. In introducing the topic of this ad-hoc

meeting, Stephen Graham, a fetal surgeon, referred to those present as a "working group" to address the issue of maternal safety.

An illustration of the continual quest for cooperation was provided in a talk presented by Dr. Graham for other practitioners at Hilltop Hospital. The presentation was given during grand rounds for obstetrics and gynecology, with most of the audience representing these two specialties. Entitled "Prenatal/Perinatal Management of Anomalies," the talk was clearly designed to "enroll" (Latour 1987; Latour and Woolgar 1987) obstetricians as allies, or members of the team, in the enterprise of fetal surgery. Not only are many obstetricians vocal critics of open fetal surgery (for reasons discussed below), but they also possess the skills and expertise in maternal health issues that fetal surgeons may be lacking or seeking. For example, preterm labor is a major problem in fetal surgery, and obstetricians identify themselves as best equipped to resolve it. Dr. Graham strategically emphasized throughout that his team is very concerned about maternal safety. Significantly in terms of establishing cooperative working relationships, he invited the obstetricians to "talk about [fetal surgery] together, both its limitations and new approaches." He remarked that surgeons are "looking to forge a new partnership." Dr. Graham closed his talk by emphasizing that the success of the Fetal Treatment Unit at Hilltop Hospital "depends on people rubbing shoulders in the hall, talking informally, and working together." In short, the presentation was a strategically delivered invitation to obstetricians to participate in the fetal surgery enterprise as a cooperative venture.

In sum, then, there seems to be an ongoing commitment to cooperation and teamwork among the practitioners who work in the fetal surgery domain. To some degree, any cooperation which is achieved is based in part on shared understandings of the work of fetal surgery. However each medical worker may conceptualize fetuses and pregnant women, the institutional shape of this domain situates the fetus as a primary locus of practice. Simply stated, the chief reason that people work together in

fetal surgery is because a pregnant woman has been admitted with a problem fetus requiring treatment. There may be ancillary reasons for the collective nature of fetal surgery, but these are shadowed by the broad aim of "saving babies." As one might expect, however, the picture of cooperative harmony painted by fetal surgeons and others in this domain seems too good to be true. While there is certainly a great deal of cooperation, as displayed in staff meetings and in operating rooms, this is often achieved despite deep and profound differences between medical workers in this specialty. As any chemist (or sociologist) knows, affinity is not the only possible reaction to mixing different elements; sometimes the end result is a volatile compound.

"Folks Are Always Rubbing Shoulders": Working Around Differences That Matter

Although cooperation is necessary for open fetal surgery to work, differences among practitioners in this domain are pervasive.[5] For example, there are both minor disagreements and major fights about how both fetuses and pregnant women are talked about and worked on; proper treatment plans; post-operative procedures; who is responsible for which work tasks; and so on. There is a seemingly infinite number of possible reasons why actors in the fetal surgery domain do not always "get along" with each other, some of which they themselves recognize and articulate.[6] A fetal surgeon, Karl Hansen, had this to say about conflict in the program: "Well, I think that any time you have a group of people, sort of management by committee, there's going to be problems. People just have different views, particularly when you have groups of

---

[5]It is important to point out that data for this chapter were collected between 1991 and 1993, and thus reflect the organizational structure of fetal surgery at Hilltop Hospital during that time frame. In follow-up interviews, I have been told that while my characterization of the conflict between different people involved in fetal surgery is accurate, it is only accurate for this specific period of time in the evolution of the fetal surgery program. There appears to have been a normalization of conflict over time, a common occurrence in medicine as new techniques are introduced and subsequently routinized (Reiser 1982; Reiser and Anbar 1986; Koenig 1988). This chapter, then, while presenting a "snapshot" of a certain phase in fetal surgery's development, may not necessarily reflect what work in the Fetal Treatment Unit looks like *today*.

[6]They may also recognize other reasons but choose not to discuss these publicly.

people from different backgrounds." Another surgeon, Tony Murphy, remarked: "But that's just because things are new, and things aren't worked out, folks are always rubbing shoulders...Sure, we've had terrible conflicts, arguments, and things that were strictly differences of opinion medically."

Yet is it entirely a case of different professional training, or are the differences between social actors in this domain more complex? Lucy O'Neill, a social worker, describes this heterogeneity in more detail: "It was a baptism by fire...Meaning that I was surprised at how, in some ways, unprepared I was for the politics of the program...We all have a slightly different vantage and orientation and perspective and cultural agenda. There are so many subtle ways in which we are different from one another, both because of our professional training and because of who we are as human beings." The profound differences between actors in this domain affect the shape and trajectory of this practice in often highly consequential ways, both locally and downstream. Next I discuss several significant areas of difference at the local level of work arrangements, focusing on ways in which these differences are made meaningful in the context of actual practices.

Different Definitions of Work Objects: Negotiating the "What" of Fetal Surgery

A major site at which differences emerge and coalesce in fetal surgery is in definitions of work objects. As discussed above, I define work objects à la Mead and Blumer simply as those material or corporeal entities imbued with meaning(s) and around which work practices are organized. Work objects might include, for example, fetuses, pregnant women, and technologies such as ultrasound. I argued in Chapter 2 and reemphasize here that the fetal patient is positioned as the primary work object within this domain. First, every fetal operation is videotaped for research and recording purposes. Taping begins after full anesthesia of the pregnant woman has occurred and after surgeons have opened her uterus, and it ends when they are

finished working on the fetus but before the uterus and abdomen have been sutured closed. This illustrates graphically what/whom is considered the important work object in fetal surgery. In addition, the Fetal Treatment Unit recently instituted a toll-free number for referring physicians and potential patients who desire descriptive information about the practice: 1-800-RxFETUS. Further, there are plans to create a Fetal Intensive Care Unit (FICU) where fetuses (and presumably "moms") can be monitored post-operatively. Currently these patients are monitored in the standard ICU by medical workers trained in both general and obstetrical acute care. Note that the name of the proposed FICU gives no indication that a fetus is still inside its mother's body during this post-operative period. In sum, then, fetuses are considered primary work objects in this domain, as illustrated by the practices discussed here.

Yet as ubiquitous as the fetal patient is in this domain, not *all* of the actors define fetuses as *their* primary, or even secondary, work objects. In a number of ways, different participants attribute diverse, sometimes conflicting meanings to fetuses and thus organize their work activities differently. This often leads to considerable strain between fetal surgeons, who define fetuses as central work objects, and other actors with different tasks and agendas. For example, most obstetricians generally consider pregnant women to be their primary work objects and are concerned with fetal health secondarily or only in relation to maternal health. Indeed, relations between fetal surgeons and obstetricians have become increasingly difficult in recent years, with the latter group being, in one obstetrician's view, slowly "pushed out" by the fetal surgeons.[7] Dr. Siegel, dissatisfied with the direction of the FTU, stated: "[We] are having trouble with [fetal surgery] because we're seeing lots of complications in women...The obstetricians, of course, take care of the maternal

---

[7]The Fetal Treatment Unit I studied is often approached by other hospitals interested in starting fetal surgery units. Fetal surgeon Jack Nelson told me that the FTU has advised a major East Coast hospital "*not* to include obstetricians from day one." In other words, if obstetricians are not invited in as co-founders of this program, then some of the problems "plaguing" the FTU at Hilltop Hospital might be avoided at other institutions.

patient." He later remarked, "[Fetal surgeons] don't take care of the woman afterward. We've had women who've not been able to leave the hospital, who've been in and out of labor for the rest of their pregnancies. [And] those are the successes!"

Barbara Greenwood, a social worker, confirmed these sentiments and described difficult relations between fetal surgeons and obstetricians: "The OBs are used to managing [maternal] patients...A lot of angry stuff between the OBs, who is going to be in attendance at these deliveries, you know, people who really didn't want to do it or believe in it. They think it's bad medicine, bad to take a pregnant woman and cut her open." This is the same informant who remarked earlier that the days of territorialism in fetal surgery were now over.

Comments of fetal surgeons are especially revealing about conflict between "baby doctors" and "mom doctors." For example, the proposed Fetal Intensive Care Unit described above has proven somewhat controversial and has yet to be implemented. According to Karl Hansen, "Anytime you have new concepts like [the FICU], you're bound to encounter some resistance...That was a new concept for many people and it led to friction." When I pressed him about the source of resistance, he remarked "Well, you know, it's just a different way of dealing with things. I'm used to doing big operations and having patients in the ICU, and some of the obstetricians and OB nurses are not used to that...They view the post-operative period as the preterm labor problem...But it was clear that patient management went far beyond just management of preterm labor, and we couldn't *not* be responsible outside of monitoring. That led to friction." Of course, monitoring means that the pregnant woman must remain in or nearby the hospital after surgery, often for several weeks until she delivers her baby.

Another fetal surgeon, Jack Nelson, described in somewhat more critical terms key differences between patients as work objects: "The unfortunate part is that the obstetricians have been taking care of the fetal/maternal pair for so long it's driven into

them...But our patients aren't like their patients. Our patients are mid-gestation fetuses, our mom has just undergone a major operation, our fetus has just undergone a major operation, there's been prolonged anesthesia, and now there's problems with pain control, volume fluctuations, and all the normal perioperative things...Obstetricians don't understand anything about perioperative management; they don't understand anything about management of a patient in the perioperative period."[8] Note the distinction here between *fetal* patients/work objects as constituting the territory of fetal surgeons, and *maternal* patients/work objects as part of the proprietary but increasingly shifting terrain of obstetricians.

Dr. Nelson ascribes such differences to professional training and background: "Basically every group of physicians have their own personality. Surgeons tend to be a little more aggressive, we tend to push harder, get things done. It's just a personality thing...The obstetricians now have seen enough problems with fetal surgery that they're absolutely opposed to it. They don't like it. They don't want it to happen. They're against it. The only reason they're going through the moves right now...is because it's protocol driven." Dr. Sigler, a fetal physiologist, echoes these points: "Well, I think it's again a turf issue. Obstetricians feel that they should be responsible for all prenatal care---care of the fetus *and* mother. And surgeons feel that the fetus is their patient and have therefore assumed some responsibility for the mother." Although professional training may be significant, it is the implementation of such training in local work arrangements which both shapes and reinforces crucial distinctions among different specialists in this domain.

The availability of direct access to fetuses is an important constraint on how, by whom, and under what conditions fetuses are defined as meaningful work objects. This is illustrated in Harrison's (1991a:10) discussion of which specialist should

---

[8]This is a somewhat ironic criticism, as obstetricians have historically, and increasingly routinely, performed cesarean sections and must have at least a passing knowledge of "major operations." Further, in a different sense of the term, moms have also viewed birth itself as a major operation.

perform fetal surgery, or rather, which specialist should be the team leader. He begins by stating that the most politically expedient solution would be to have each specialist do his or her part of the overall procedure. This would mean that obstetricians open and close the uterus, and the pediatric surgeon operates on the fetus. This easy solution is, according to Harrison, "likely to keep team members comfortable in their accustomed roles." Yet he goes on to state that this practice is not likely to yield the best outcomes because "it assumes that traditional skills will suffice; that is, that obstetricians can close the uterus as they do in the case of an empty uterus and that the pediatric surgeon can do with a fetus what he learned in a neonate. Neither is true." He argues that "tag-team surgery is never ideal," particularly where exposure and closure of the fetus by hysterotomy is complicated by pre-term labor problems. Thus, despite the rhetoric of teamwork, it seems that a division of labor by extant specialties may not work or be construed as ideal. In terms of defining fetal work objects as the province of one set of specialists, Harrison (1991a:10) claims that "fetal surgery cannot develop and will not succeed unless a few surgeons are willing to devote considerable time and effort to developing, practicing, and perfecting all aspects of this new procedure."

To further complicate matters, other workers in the FTU define their work objects quite differently from both the fetal surgeons and the obstetricians. For example, one of the social workers I interviewed, Lucy O'Neill, is troubled by fetal surgery because, in her words, "every baby was dying. Every step of the way, we've been thwarted...by consequences of surgery that have high morbidity and high mortality for these babies." Because negative outcomes often seem to create or intensify conflict,[9] this social worker decided that she would be "an advocate for the parent." Yet differences in status within the FTU between social workers and

[9]Dr. Hansen told me that if everything "worked right," everybody would "get along fine." Dr. Truitt remarked, "If everything was red, white, and blue banners flying all the time about the successes, then believe me, there would be no conflict. Everybody would be so happy. The only conflicts would be who got to stand first in line for the laurels. We're more likely to have conflict when we have failures."

physicians often make this difficult. O'Neill is frustrated in her attempts to advocate for the pregnant woman by surgeons more intently focused on fetuses. For example, women who are prime surgical candidates clinically may not be good candidates psychosocially (discussed below). O'Neill's judgment about a particular patient was recently challenged, leading her to remark: "I was incensed about it...At that point, my confidence was shaken and I felt that if I'm going to be the psychosocial person on this team, I'm going to have to have the support of the members of the team." While her recommendation was ultimately supported by an outside psychiatrist, she felt that the incident "forced [her] to look again at [her] role and [her] interactions with the team."

There are a number of divergent positions on who or what are, and are not, work objects in fetal surgery. As the examples above make clear, different participants ascribe different meanings to work objects in this domain. For fetal surgeons, fetuses are first and foremost patients and objects of treatment-based work practices such as surgery. For obstetricians, pregnant women are (usually) the first and most important patients and objects of maternity care, while fetuses are secondary work objects. Most obstetricians do not completely reject the notion of a fetal patient; indeed, one of the striking developments in medicine in recent years is the emergence of maternal-fetal medicine as a replacement for standard obstetrics (Creasy and Resnick 1994). However, conflicts between obstetricians and fetal surgeons tend to center on other aspects of treatment, such as how to keep pregnant women healthy while operating on them *solely* for the benefit of their fetuses. For social workers, fetuses are only direct work objects in a tertiary sense; yet one social worker quoted above was concerned that too many fetuses were dying. For social workers, the pregnant woman and her family are the primary work objects and are defined in terms of psychosocial care rather than surgical treatment, even while outcomes may be of great concern.

In sum, work practices are organized around the meanings that each work object has for different actors. There is a certain medical "logic" at work here in terms of identifying what to do next in the clinical setting (Berg 1992). That is, if the fetus is a patient, then it must be treated. If the pregnant woman is a patient, then she (and secondarily her fetus) must be cared for. If a pregnant woman and her partner need psychosocial care, it is to be provided by the appropriate person, generally a social worker. Yet despite these key tensions surrounding different work objects and practices, the Fetal Treatment Unit *qua* organization is collectively geared toward "saving fetuses," which continue to be *institutionally* defined as the most significant work objects. Who, then, decides what are primary work objects? Under what conditions? With what consequences? How do institutional hierarchies shape this process?

In the examples below, I explore additional dimensions of difference, both of which are related to definitions of work objects and their "sitings" within particular locales. Each of these examples represents a possible consequence flowing from diverse yet hegemonically ordered meanings attributed to work objects in fetal surgery.

Different Criteria for Patient Selection: Negotiating the "Who" of Fetal Surgery

Different actors in fetal surgery use different criteria for patient selection, or who is considered a good candidate for treatment, based on their definitions of work objects.[10] Clearly, if there is disagreement over who/what a patient is, then there is likely to be conflict over how to select for patients. Fetal surgeons generally define selection in terms of fetuses (Harrison 1991b), while obstetricians consider maternal health a priority; both groups tend to rely primarily on what we tend to think of as

[10]Not all patients referred to the FTU I studied end up having fetal surgery, which is only one, albeit the most invasive, of several available treatment options. Other options include non-surgical medical interventions such as drug therapy, aborting the fetus, and/or not treating at all.

"clinical" criteria. In the clinical literature (Harrison 1991a), guidelines for patient selection suggest that a fetus should be a singleton (i.e., not a twin) prenatally diagnosed and found to have abnormalities. The family should be fully counseled about the risks and benefits of surgery. Further, a multidisciplinary team should be used during treatment, and high-risk obstetrical and intensive care units should be available. Last, bioethical and psychosocial consultation should be made available for both practitioners and patients. In local practices, however, these carefully stated global guidelines are not necessarily adhered to. Depending on circumstances and conditions, some factors may take precedence over others in the selection process. These practices reveal how "clinical" decisions are often rooted in non-clinical priorities.

For example, one fetal surgeon described selection and treatment considerations for congenital cystic adenomatoid malformations (C-CAM). This is a condition in which a benign lung tumor takes up too much space in the chest and can cause fetal hydrops, or excessive accumulation of fluids in the body's tissues and cavities leading to heart failure. The disease is particularly dangerous because fetal hydrops can cause pregnant women to become quite sick, and to possibly die, through the mechanism of placental transfer. As fluids are released from the placenta into the woman's bloodstream, she may develop severe preeclampsia (hypertension) or pulmonary edema (accumulation of fluid in the lungs). A fetal surgeon stated, "this is called the *maternal mirror syndrome* because the mom's condition begins to mirror that of the fetus." After several fetuses died either during or after C-CAM surgeries, the fetal treatment team determined that the bigger the tumor, the less likely a fetus (and possibly the pregnant woman) is to survive surgery. As one fetal surgeon pointed out regarding the initial fetal deaths, "Along the way, you actually learn more from things that are not successful than from things that are successful." Laboratory research in fetal lambs subsequently generated a technique for resecting lung tissue, deflating the

chest, and "curing" the hydrops. According to this surgeon, patient selection for C-CAMs currently rests on a *clinical* evaluation of fetuses which includes assessment of lung tumor size, gestational age, and the degree of advancement of fetal hydrops.

Yet as the above surgeon's comments indicate, this "clinical" evaluation is also related to the broader research goals of experimental fetal surgery. As one fetal surgeon pointed out, there have been "a number of biologic spin-offs from this work." These include, for example, wound healing research in which scientists investigate why fetuses heal without scars;[11] the "preterm labor problem," including introduction of new drugs and technologies to prevent it;[12] and a host of other questions. Not everybody involved with the Fetal Treatment Unit is enthusiastic about these scientific "advances." An obstetrician remarked: "The [fetal] surgical group constantly wants to introduce new things that have not been thoroughly tried...There's a very different approach to how experimental things should be introduced." In response to probing about the ethics of experimentation, this same informant sharply stated, "Are you asking me whether I think the human pregnant woman and fetus should be used as an experimental animal?...I think that is what's happening."

The contradiction between what are defined as "clinical" and "non-clinical" factors in selection is particularly evident in conflicts between fetal surgeons and others, such as social workers, over criteria for surgery. Consider the situation in which a social worker's evaluation was dismissed in favor of narrow clinical criteria, with particularly unsettling consequences. April Saunders, a 19-year old white, single

---

[11]There is considerable excitement about fetal wound healing research, as discussed in Chapter 4. As one fetal surgeon put it, "Ten years ago no one would have predicted a huge investigative effort now in trying to figure out how the fetus can heal without scarring...If the fetus can teach us how he or she can heal without scarring, we can use that same blueprint to treat problems after birth. That would be incredible." Possible applications may include, for example, cosmetic surgeries (both reconstructive and elective) and use in the cosmetics industry.

[12]A fetal surgeon stated that "the preterm labor problem is to fetal therapy what rejection is to transplantation. And we're working like crazy to come up with the medication, like cyclosporin was for transplantation, to treat the preterm labor problem. If folks here can do it, then that would have implications beyond our little tiny fetal therapy enterprise. That would have implications for a huge health problem."

woman with one child on public aid, whose fetus was diagnosed with a congenital diaphragmatic hernia, was referred to the FTU for treatment. Below are excerpts from my fieldnotes taken at a meeting during which Saunders' treatment was discussed:

> The meeting began with a description of the patient to be operated on. Ultrasound had been abnormal, indicating a possible diaphragmatic hernia. The woman smokes (mentioned by Graham as a health status indicator) and is on public aid, at which point Graham commented that the only thing that means for the Fetal Treatment Unit is they won't be paid. Social worker Barbara Greenwood responded to Graham's and Siegel's questions about Saunders' background and social situation. Greenwood commented that April is smart, "has religion," knows that her baby might die, and is "quite remarkable for a 19-year old," which garnered several grunts of agreement from the others present. According to Greenwood, the bottom line is that April knows the risks and wants the surgery. Based in part on Greenwood's assessment of April's emotional condition and Siegel's and Graham's medical assessments, the decision was made to go ahead with the surgery. They decided to schedule it for 8:00 a.m. on Thursday. April would be admitted to the hospital on Wednesday evening.

It is interesting to contrast this record of the decisionmaking process with this social worker's recollection and interpretation of it. According to the social worker, April Saunders "had been a product of foster homes...She had a little kid, she was in a second relationship, new partner, *but she was like a perfect physical specimen.* She was young, she was strong, the baby had the right liver. And it was one of the real successes of the program. But in the end she took him home and shook him, shook

her baby, and he was taken away."[13] Here the social worker points out that even when a case seems ideal from a clinical point of view, unknown and unanticipated factors may influence the outcome. Her narrative suggests that fetal surgery may be a traumatic experience for pregnant women, and consequently for their families downstream, particularly when a pregnant woman's life circumstances and social support networks are less than optimal, as in this case.

While social workers do not dismiss clinical criteria or outcomes, which are often quite serious, they are most interested in whether a pregnant woman will be able to psychologically withstand the rigors of fetal surgery and has adequate social support in place. These are issues that fetal surgeons and obstetricians, focused on clinical factors, consider only peripherally in practice. Thus, emphasis on treating fetal patients/work objects draws attention away from other participants and considerations in fetal surgery, such as the physical and emotional health of pregnant women and their families. The social workers in the Fetal Treatment Unit strive to provide adequate psychosocial care to their constituency, but are constrained in how much they can actually do by clinical practices aimed at "saving" fetuses and by institutionalized hierarchies of hospital care in which social workers typically have little say. Simultaneously, although surgeons and obstetricians consider psychological and social factors, these criteria often seem to play second fiddle to clinical criteria. Thus, "patient selection" is one set of work practices which in part shapes the conditions under which work objects are defined in this domain, while definitions of work objects in turn influence patient selection.

---

[13]Emphasis added.

Different Views of a Disease and Its Treatment: Negotiating the "How" of Fetal Surgery

The third area of difference concerns fetal disease or, more specifically, what should or should not be done about a particular disease, namely congenital diaphragmatic hernia (CDH). Not all fetal surgical treatments are as controversial as CDH and are therefore less interesting in terms of interactional dynamics. For example, repairing blocked urinary tracts is seen as somewhat "routine" in the overall fetal surgery enterprise. What makes CDH particularly contested is the very high fetal mortality rates, discussed below. Other procedures have been far more "successful" than open surgery for CDH in terms of fetal mortality. CDH is a condition, diagnosable by ultrasound, in which fetal abdominal organs migrate upward into the chest through a hole in the diaphragm. The disease is often fatal because normal, healthy lung development is impaired and fetuses die in utero of respiratory failure. Sometimes an infant born with CDH can be operated on successfully, and many CDH cases are treated after birth. Fetal surgeons pursue *prenatal* surgery for CDH with the hope and expectation that early treatment will prevent the condition from worsening. Their prevailing clinical logic is that prenatal treatment will enable an adequate growth period in utero for fetal lungs following surgery. However, fetal mortality for CDH cases is near 60% (Harrison, Adzick et al. 1993), and even fetuses who survive are not completely healthy; *all* surviving fetuses require some additional postnatal surgery and follow-up. For these reasons, CDH has become a sort of rallying cry around which critics of fetal surgery organize their resistance, while fetal surgeons struggle to meet the challenges posed by this difficult-to-treat disease.

Fetal surgeons are enthusiastic about prenatal treatment for CDH, even while recognizing that their lack of success makes the procedure controversial. For example, the FTU received a large grant from the National Institutes of Health to conduct a controlled clinical trial of CDH cases. According to fetal surgeon Tony

Murphy, there is a great deal at stake in the study: "We've just begun this NIH trial, and we've been in starts and stops, moratoriums, you name the process, we've been through it. It's been extremely frustrating, and it's hard to know if formal diaphragmatic hernia repairs will be possible before birth. We're hoping that this trial will have the answer, so we can tell the rest of the world that yes this is worth doing, or no, stop doing it, and you have to just take your chances after birth." So far, outcomes have been discouraging to surgeons because many fetuses have died. Yet the fetal surgeons keep trying and hoping. As Jack Nelson points out, "Most of the mistakes, or most of the things we've learned, have been the result of frustrations doing the first few clinical diaphragmatic hernia repairs. And things that you couldn't have predicted no matter how many fetal animals you've done. So that's a very controversial area of treatment." When I mentioned that I had heard some negative criticism about the CDH cases from other practitioners, Dr. Murphy remarked: "But that's fine, that's good, at least now we can sort of put it to the test and see once and for all, after incredible painstaking review by the NIH. That's the way it gets sorted out."

While fetal surgeons continue to investigate surgery for CDH, other participants have become increasingly outspoken in their criticisms of the practice. Obstetrician Walter Siegel remarked, "I think now you'll get divergent opinions--they are still enthusiastic about [CDH], we are definitely not and I'm willing to go on the record saying that...I would not recommend that any of my patients have open CDH surgery. The chance of survival is much greater to not have surgery and deliver in a tertiary center than the surgical survival is right now. There are just problems that have never been solved." When I asked him if he thought the conflict had to do with different professional training, he replied angrily, "It's not a disciplinary split! Get the actual numbers of how many CDH cases have been done and what the success rate is, and how many of those kids are living. Then compare that to the fact that if you

come in here and have a CDH that we diagnose prenatally, and you deliver in a tertiary center, there's very good evidence that you will have a 40% survival rate. And you will draw your own conclusion as to whether you would ever have such surgery or whether you would ever suggest to a patient that they have it." With respect to *postnatal* surgery for CDH, he went on to say that "[the pediatric surgeon] still gets to operate on them, but it's a less sexy thing and it's something everybody's doing."

Social workers and obstetricians, who may disagree about criteria for treatment, often find themselves on the same side of the CDH debate. Barbara Greenwood is deeply disturbed by these cases; in her words, "I found myself feeling like maybe this wasn't the best thing we were doing...it would be a relief to me if they weren't doing fetal surgery for the diaphragmatic hernia." Her reasons are similar to the obstetricians' and have to do with the mortality rates. She points out, "I can't recall very many healthy survivors of the fetal surgery program [for CDH]." And like the obstetricians, social workers express a certain amount of distrust for the fetal surgeons: "I was wondering about the presentation and whether we hadn't been manipulating statistics in a way to make it sound like this was an alternative to these kids going to term...I really felt although they were trying to be honest, it was very hard to really paint an accurate picture and expect that anybody would actually do a thing like this, put themselves through this." As we spoke about the CDH cases, she grew visibly upset and finally remarked, "I don't know how many more moms and babies we can bring up to the altar of fetal surgery with the outcomes that we're having...It's not as though you go through this and you're gonna have a healthy kid at the end!"

Both the obstetricians and social workers feel that the CDH cases are in part motivated by professional interests of fetal surgeons. After all, fetal surgery has been referred to as the "final frontier" in reproductive medicine, and has certainly been a career-making enterprise for the surgeons in the FTU. In response to my question

about why fetal surgeons continue to do CDH surgeries in the face of high mortality rates, Dr. Siegel replied bitingly, "Well, they believe in themselves. They believe they're going to stamp out disease and save babies...And I think what they're doing at this point is unfair and it borders on being immoral. Therefore our group is no longer part of it." And Greenwood remarked, "There are kids who have hernias the size of the Grand Canyon...And Dr. Graham is the kind of guy who really likes to take on something like diaphragmatic hernia, it's one of the most vexing problems. Sometimes I look at [the fetal surgeons], I step back, and I think, Can't they see that this isn't really going very well? When are we going to say gee, this isn't really working? Maybe we need to move on to something else. But the further along they get, the more dogged they get in their determination to meet every problem with a solution."

Conceptualizations of fetal disease relate to definitions of work objects in ways similar to criteria for patient selection. The meanings that actors have about work objects order their work practices, just as work arrangements simultaneously shape the meanings given to fetuses and pregnant women. Fetal surgeons, for whom fetuses are central objects of work, are ostensibly dedicated to "saving" their patients, though they may well have additional commitments and goals. Thus a central meaning ascribed to fetal work objects by surgeons is that the fetal patient *qua* work object must be repaired. Within this framework of meaning, attempting to correct a lethal fetal disease surgically is seen as the most logical action taken by surgeons. In turn, acting on this meaning by operating on a diseased fetus contributes to a social definition of the fetus as both patient and work object.

Neither obstetricians nor social workers consider the fetus to be a primary work object despite the Fetal Treatment Unit's collective institutional definition. For these actors, work practices center not on "saving" the fetus clinically, but rather on saving fetuses from fetal surgeons through activities which promote maternal and fetal health and well-being. These may well include criticizing fetal surgeons for treatment

plans and outcomes that seem inconsistent with overall goals of healthier babies and "moms." In their view, the outcomes of surgery for congenital diaphragmatic hernia are not sufficiently positive to risk the physical and emotional health of pregnant women. Thus CDH, which has so far proven remarkably resistant to prenatal treatment, occupies different positions in the system of meanings held by each set of actors in the fetal surgery domain about their work. Yet despite both obstetricians' and social workers' concerns about maternal health and less than satisfactory fetal outcomes, fetal surgeons continue to attempt prenatal surgical repair of diaphragmatic hernias. In short, fetal surgeons more so than other medical workers here continue to dominate the trajectory of fetal surgery as an emergent specialty focused on the fetal work object.

It is insightful to compare fetal surgery for CDH and other conditions with other, less invasive fetal treatments which are not as redolent with controversy. Recall from Chapter 3 Dr. Adamsons' comments about how fetal surgery tends to legitimate many non-surgical fetal treatments which have now become routine. This was reinforced at a 1993 conference on Fetal Research and Applications sponsored by the Institute of Medicine, where fetal surgery was a hot topic on the agenda. Speakers discussed the history of the fetus as a patient, percutaneous umbilical blood sampling (PUBS), diagnostic and therapeutic advances using embryoscopic techniques, and non-invasive fetal treatments such as bed rest and transplacental drug delivery. All of these topics sparked much interest and minimal contestation. In contrast, the talk on surgical fetal treatment generated a flood of remarks about its appropriateness and effectiveness. The obstetrician who presented the talk, Walter Siegel, remarked, "There are very few indications where this will be useful because you can't get there early enough. Whereas this is very sexy, it's not very practical. I don't think we're going to save many fetuses." Another obstetrician agreed, stating that "there is more to fetal treatment than surgery." Most commentators pointed to

high fetal mortality rates and the degree of invasiveness as limiting the success of the surgical approach to fetal treatment. Almost all participants seemed to agree that prenatal gene therapy is the "wave of the future." Stated bluntly, problems associated with fetal surgery, the "sexy" outlier in fetal treatment, tend to make less invasive fetal treatments appear more reasonable, even where maternal health and safety issues may be salient.

Conclusions

This chapter has shown that fetal surgery is a negotiated yet fluid order, given institutional and practical shape through the interactions and work practices of its participants. As a heterogeneous enterprise, fetal surgery is characterized by cooperation, conflict, and a range of other interactional dynamics. Participants coalesce around fetuses and pregnant women in different ways, and there is both agreement and discord surrounding who or what is the work object in fetal surgery. These interactional dynamics shape such aspects of fetal surgery as patient selection and definitions of diseases and their treatment. Differences between practitioners are thus mobilized in certain ways to produce a negotiated order, an outcome which supports the overall institutional goals of the Fetal Treatment Unit while differences may continue to rage internally. This *politics of difference* refers to how heterogeneity is mobilized and articulated in different ways and for different purposes.

The politics of difference also means that while there are many participants in this domain, some are heard and seen more clearly than others. Focusing on how different actors define work objects and organize their work practices highlights the many alliances and cleavages formed in this domain. Fetal surgery may well be a negotiated order, but it is continually evolving in response to other factors shaping negotiation. A context in which fetuses are defined as primary work objects leaves little room for the practical differences among actors to filter up to the institutional

level. Most significantly, fetal surgeons have been successful in framing fetal surgery in line with their own commitments and interests. As Jack Nelson remarked, "None of [the other practitioners] would be needed, it would be down to a single group of physicians, if we could just make them realize the goal is to get the fetus to survive the operation. We need a czar...We need to *be* the czar." The point here is not to demonize fetal surgeons or to impugn their commitments to healthier babies, but rather to show how negotiations are patterned within and by institutional hierarchies, access to work objects, and investments in human fetuses.

Focusing on the politics of difference also means carefully considering the broader implications of experimental fetal surgery and how local work practices might seep out of the operating room and into other spheres of social life. For example, surgeons' emphasis on fetal work objects constructs pregnant women as barriers which must be passed through in order to reach the primary patient. Although there are actors in this domain who advocate for pregnant women, such as social workers, the interactional fabric of fetal surgery is woven in such a way that being an advocate for anybody other than a fetus is *very hard work*. The social workers, self-proclaimed "handmaidens" to the clinicians, are often unable to address psychosocial concerns of pregnant women because clinical criteria applied to fetuses take precedence and because of where social work is positioned within the medical hierarchy. While obstetricians also attempt to advocate for pregnant women, their more circumscribed clinical orientation often precludes attention to important psychosocial and emotional issues. These dynamics have a number of implications, including possible compromised fetal and maternal health and well-being. This is not to suggest that if social workers had more power and were able to advocate for pregnant women, fetal surgery would be unproblematic. The issues here are much more complex than simply replacing "clinical" concerns with "social-psychological" ones. Rather, an important

task is to determine where the "social" and the "clinical" overlap, and how the politics of difference impact pregnant women's health.

As an emergent and contested specialty, fetal surgery is in an uncertain position. The longevity of fetal surgery may well be shaped by the local factors discussed here, as well as by broader developments in the U.S. health care system and the cultural politics of reproduction. The salient differences related to definitions of work objects will likely continue to occupy participants in this field, even while they strive cooperatively to meet the Fetal Treatment Unit's institutional aims of "saving fetuses" from certain death. Yet how, and if, these differences will be resolved is contingent upon an array of factors. There is little reason to believe that contestation will simply cease should fetal surgeons achieve control over the terrain of fetal surgery. If fetal surgery becomes a routine medical specialty, the differences pointed to in this chapter will undoubtedly continue to shape both global and local definitions of fetuses as work objects and as patients, with implications for pregnant women's health. Current practices in this contested domain are indeed shaping the future of fetal surgery.

Chapter 6

"Heroic Moms" on the Reproductive Frontier: Maternal Practices in Fetal Surgery

"The physician's...voyeuristic penetration of the murky darkness of the womb brings the fetus to life--not only because visual access to the fetus permits him to diagnose disease and prescribe treatment, but also because his seminal gaze rescues the fetus from the oblivion of its union with the mother."
(Adams 1994:157)

"Love is always ambivalent and dangerous. Why should we think that it is any less so between a mother and her children?"
(Scheper-Hughes 1992:353)

Previous chapters have emphasized the fetal work object and its embeddedness within the social and political organization of medical work. There I demonstrated the symbolic and institutional erasure of pregnant women through clinical practices centered on fetuses treated as unborn patients. Yet pregnant women, as embodied actors, are very much a part of experimental fetal surgery. They, too, are work objects in this domain and they, too, act on behalf of fetal work objects. In treating the fetal patient, medical workers must interact closely with pregnant women without whose cooperation the specialty would not exist. In this chapter, I address women's vital participation in fetal surgery, focusing on the tensions engendered by their multiple identities as both working subjects and work objects. Analytically, I reframe fetal surgery such that pregnant women remain in the picture as both engaged and implicated actors and not just passive technologies of fetal access, although these constructions are salient as well. I define fetal surgery not as a pediatric concern but rather as a women's health issue with significant implications for women's reproductive lives and futures.[1]

---

[1]Data for this chapter were obtained from interviews with pregnant women and their families, videotapes of pregnant women discussing their experiences, clinical and popular literature, and ethnographic research

In order to grasp some of the tensions surrounding pregnant women's relationship(s) to fetal surgery, one must first understand the emergence of the *maternal/fetal conflict* paradigm in its modern institutional and disciplinary forms. Within certain ethical frameworks (Chervenak and McCullough 1985; Steinbock 1992), for example, fetuses are accorded interests on the basis of their moral value as potential persons. Given the material location of fetuses in women's bodies, assignment of fetal interests is often constructed as in opposition to pregnant women's interests. A similar perspective exists in the American legal system, which has witnessed an expansion of the fetal rights framework in recent years and a corresponding diminution of women's reproductive autonomy (Johnsen 1986; Daniels 1993). Fetal rights are increasingly conceptualized as being in direct conflict with pregnant women's rights and interests. Like ethical and legal practices, fetal surgery is also implicated in the construction of an ideology of maternal-fetal conflict in which women and their fetuses are believed to have different, even competing, interests and needs (Nelson and Milliken 1990; Mattingly 1992). This dissertation has traced some of the ways in which an ideology of maternal/fetal conflict is embodied in fetal surgery, where the interests of the fetal patient are seen as paramount and pregnant women are conceptualized as necessary tools for enhancing fetal access. Yet, from a women's health perspective, a framework characterized by maternal/fetal conflict is invalid, or at least questionable, empirically and politically.

One way of challenging the maternal/fetal conflict model is by emphasizing an array of *maternal practices* in fetal surgery. Scheper-Hughes (1992:341) defines maternal practices as a "pragmatics of motherhood" shaped by "a matrix of images, meanings, sentiments, and practices that are everywhere produced." Contrary to essentialist perspectives which argue for a naturalistic mother love rooted in maternal thinking (e.g., Ruddick 1980), Scheper-Hughes (1992:356) instead attends to "the

---

in the Fetal Treatment Unit at Hilltop Hospital. See Appendix A for a discussion of some limitations of these data and access problems encountered during this phase of fieldwork.

reality of maternal thinking and practice grounded in specific historical and cultural realities and bounded by different economic and demographic constraints." Shaped by culture and context, maternal practices are those interactions and actions women participate in on behalf of (their) children and fetuses. The concept encompasses a whole range of maternal desires and responsibilities, and provides a useful fulcrum for examining the work that pregnant women do in fetal surgery. My use of the term here is meant to showcase pregnant women's experiences and interests, and to argue for a maternal/fetal relationship characterized by something other than conflict.

For example, a number of informants have remarked that the pregnant women in fetal surgery are "heroic moms." But what constitutes a heroic mom? What kinds of maternal practices are valued in this domain? What types of work do women do in fetal surgery? As a step toward answering these questions, I draw on interactionist perspectives to formulate pregnant women as *engaged* actors in the sense of being actively involved in or committed to the enterprise of fetal surgery.[2] An ongoing theoretical focus in interactionism is how people take account of or orient themselves toward other people and things in meaningful ways. People have a variety of commitments, interests, and desires toward that which is meaningful, and act on these commitments to the extent that they are able. Pregnant women tend to assume an engaged stance toward their fetuses and act on the basis of their fierce commitments, in part because fetuses are meaningful to women (Rothman 1989; Sherwin 1992). Here I address women's engaged participation in experimental fetal surgery, and raise some important questions about the implications of *their* work and *their* commitments to fetal work objects. As the physicians, nurses, social workers, and other practitioners are at work in the fetal surgery setting, so too are the pregnant women.

---

[2]Webster's Ninth New Collegiate Dictionary (1985) defines *engaged* as: "involved in activity; greatly interested; committed." All of these definitions apply to women's participation in experimental fetal surgery.

Specifically, then, this chapter attempts to do several things. First, I focus on pregnant women as engaged subjects through an analysis of varied maternal practices, including women's choices and politics in fetal surgery, the organizational and body work involved in fetal surgery, and women's assumption of health risks. I next address several tensions in fetal surgery shaped by the material significance of the maternal/fetal relationship, including maternal management strategies, the informed consent process, and the significance of lay versus professional control in clinical decisionmaking. I show that pregnant women are simultaneously working subjects and work objects; engaged and implicated; part of social and corporeal maternal/fetal relationships and enmeshed in discourses of maternal/fetal conflict. Rather than attempting to resolve these tensions, I instead close with a discussion of fetal surgery as a women's health issue infused with reproductive politics. Reframing fetal surgery in this way brings into relief some of the more pernicious implications of this practice for women, while also recognizing that women may indeed, here as elsewhere, be agents of their own medicalization (Leavitt 1986; Bell 1987).

"Anything We Had to Do to Give the Baby a Chance": Women Engage Fetal Surgery[3]

In the 1960s in Auckland, New Zealand, obstetrician Florence Fraser began encouraging pregnant women to talk to their fetuses. She suggested that women "think of their babies as personalities" *before* birth, as this would help the bonding process in the neonatal period. Fraser believed fetuses to be "people from a very early stage," and saw no conflict in helping pregnant women do the same. She found very little resistance to this idea from her patients; the women were eager to engage in any practice which would facilitate a healthier pregnancy and intensify maternal/infant bonding after birth. Fraser told me, "The mothers were very involved

---

[3]Quote from Kolata (1990:92).

with their babies and what was happening. I believed that was terribly important. [Bonding] is not scientific, I know, but it did make a difference." She felt that women's involvement with their fetuses was especially useful in fetal surgery cases, where procedures were sometimes complicated, fetuses often died,and Rh-negative women often needed to return to National Women's Hospital for subsequent fetal transfusions.[4] Fraser found the fetal transfusion patients to be an engaged group of women, enthusiastic about interventions which might help save their babies from hemolytic disease.

As in 1960s New Zealand, fetal surgery patients in the U.S. today are a committed, engaged, hard-working group of women. They may be configured in a variety of ways through work arrangements and clinical practices--fashioned into technomoms--but they are also active participants in the enterprise of fetal surgery. They are there, in the operating room, because they have made a very complicated decision to seek treatment for an ill or defective fetus. Throughout their experiences with fetal surgery, these women do an extraordinary amount of work on behalf of their unborn babies. Indeed, their engagement is essential to definitions of the fetus as a patient. As Dr. Nelson remarked, "Why is the fetus a patient? It's not a patient unless mom says it's a patient." While simplifying the historical, technological, political, and cultural processes through which the fetal patient has emerged, Nelson's comment nonetheless highlights the crucial role of pregnant women in birthing this new social entity. Below I focus on some key maternal practices in fetal surgery, emphasizing women's subjectivity and commitments as engaged actors in this domain.

---

[4]Fraser told me that when she started at National Women's Hospital, the fetal survival rate for transfusions was around 45%, and had risen to about 60-70% by the time she left. See Chapter 3 for a more detailed discussion.

Wanting a "Miracle Baby": Women's Choices and Politics in Experimental Fetal Surgery

Given the experimental nature of fetal surgery and the significant risks associated with the procedure, it is almost impossible not to be curious about the full range of women's motivations to seek intervention. This is especially so in that the pregnant women who come to Hilltop Hospital on behalf of a sick fetus are also presented with other options: abortion, non-surgical treatment, post-natal treatment, or no treatment at all. All of these different trajectories represent aspects of pregnant women's work, including emotion work (Hochschild 1983) such as grief and recognition of loss when fetal deaths occur. That fetal surgery is one choice among a handful of possible treatments also raises the question of women's willingness to bear and raise an impaired baby in a society where this is a difficult task. For example, Rothman's (1986) eloquent study of amniocentesis presented the voices of many women who chose prenatal diagnosis out of fear of fetal disability. Is fetal surgery, like prenatal diagnosis, seen by pregnant women as a way to increase their odds of having a healthy baby? If so, there is a cruel irony here in that fetal morbidity and mortality statistics for fetal surgery suggest that even *with* treatment, an impaired baby is highly likely if there is any baby at all. Thus, just as the politics of reproduction frame experimental fetal surgery, so also do disability politics.[5]

Dr. Nelson, quoted above, is not the only informant to recognize pregnant women's important role in constructing their fetuses as patients. Of all the motivating factors described by informants which shape a woman's participation in fetal surgery, perhaps the most significant is the desire to save her baby from almost certain death. All of the conditions which are currently being treated by fetal surgery are considered terminal if left untreated. This is a powerful incentive for women in reconceptualizing

[5]I raise this issue because it seems to be an important component of fetal diagnosis and treatment. Yet, because disability was not a salient theme in my data, I do not pursue this theme here. A number of other scholars have explored the relationship between reproductive practices and disability politics (e.g., Clarke 1984; Finger 1984; Rapp 1984; Saxton 1984).

their fetuses as unborn patients. It is, for example, reflected in the introduction to the patient education video produced by the fetal surgery team: "This videotape follows a number of courageous mothers, struggling with the decision of how to save the life of their unborn child." It is also articulated in women's own voices as they explain their intensive focus on their fetuses. One patient, Debbie, remarked, "I was so focused on the fetal surgery and her [the fetus'] operation and what it entailed, that I don't think it dawned on me that *I* was going to go through major surgery."

Marla, a patient whose fetus died one month after surgery, stated "You can look at statistics any way you want. When it came down to it, it was more an intuitive feeling, that *this was the way to go*. Because you can look at facts and analyze the risks, and in the long run you just have to go with your gut reaction." Because of their tremendous efforts in crafting fetal patienthood, the pregnant women are often described by clinicians as "heroic moms." Dr. Nelson stated, "We're not dealing with a standard mom. In fetal surgery, mom has taken this penultimate sacrifice...I ask them all [why they want to do this] and they all want to do it because they want their baby. It's not really complex for them, it's typical of most women." And perhaps of many men, as well. Marla's partner, Dan, succinctly described their reasons for selecting fetal surgery: "We really wanted this baby." Marla stated, "Don't second-guess yourself. Just go with whatever decision you make because it's the best one with the information you have at that particular time." In short, the "best" decisions for these women and their partners involved selecting an intervention which transformed their fetuses into patients rather than certain casualties.

Not having access to many of the patients meant that I could not fully explore why some women choose to conceptualize their fetuses as patients and other women with similarly affected fetuses do not. However, many medical workers in this domain were quite forthcoming about their perceptions of why women opt for fetal surgery. For the most part, medical workers acknowledge that women engage fetal surgery

within the broader context of their lives. Lucy O'Neill, a social worker, illustrated this well:

> "What's the story? 'I'm Catholic, I wouldn't have an abortion, I want this baby no matter what, I love this man in spite of what my mother says, I want this baby, I know it seems crazy but I really want this baby to have every chance. I've thought about this, I am committed to this, I know the baby may not live, but I don't want to take the chance of going to term, I don't want to carry a baby with a potentially lethal lesion. If I'm going to do something about it, I want to do it now.' That's a very common story from women at 18 and at 30. 'I don't want to spend the rest of this pregnancy agonizing over this, I want to do something about it now. This is something to do, and if it works it's going to change the course of this baby's outcome. And even if there's only a small chance that it'll work, I want to do it.' There are many women who do it because it's there, because it exists, because there's someone like Dr. Graham who says, 'This is a shot. Stick with me.'"

O'Neill went on to argue that in addition to women's desire to save their babies, they may also be motivated by the perceived benefits of involvement in an experimental protocol. She told me, "There are people who are just transfixed at the prospect of coming out here." She situated this within the context of the significant work the fetal surgery team does in inviting patients to participate in experimental fetal surgery: "We do a number, I tell you. We take care of them, we feed them, we worry about them. There are people who go through this process who get more attention in the course of time they're here than they have in their lives or ever will

again. We are an incredibly nurturing bunch, we're very nice to people. And we are intentionally nice."

Barbara Greenwood, another social worker, told me that she thought patients were sometimes so impressed by the surgeons that they based decisions on personal commitments and loyalty. She said, "The ones who come here are very committed. They are adoring of Dr. Graham and Dr. Murphy, and there are a lot of babies named Stephen and Tony because they name their kids after them. Because they are extraordinary surgeons, and they have integrity, they're kind, they're devoted, they're committed to their work, they're really extraordinary people to work for." Greenwood felt that patients were very excited about becoming part of a clinical research team, with these charismatic, renowned, and caring fetal surgeons at the helm. She stated, "Everybody takes something away from this. Patients are part of the team. It gives them a sense of meaning. They become part of medical science and it jacks them up."

Unsurprisingly, reproductive politics also imbue and mold women's choices in fetal surgery. Almost everybody I talked to discussed the relationship between women's beliefs about abortion and their decision to seek fetal surgery. According to many informants, most of the women who choose fetal surgery hold anti-abortion political views and likely would not choose abortion as a treatment option. This should not be surprising. After all, if a pro-choice woman's fetus is found to have a serious, potentially lethal defect, she is more likely to select abortion as an option than a woman who is opposed to abortion (Rothman 1986). Although pregnant women of all political shades may construct their fetuses as socially meaningful and/or as potential persons, pro-choice women may be less disposed to invest in definitions of fetuses as unborn patients. They are also more likely to acknowledge important physiological and social differences between fetuses and babies.[6]

---

[6]See, e.g., Luker (1984), Petchesky (1990), and Rothman (1986) for a fuller discussion of women's multiple positions on abortion and the contexts in which they make difficult reproductive decisions.

Although I did not talk to all of the patients about their reproductive politics, I did visit one woman and her husband who were very articulate about how their views on abortion influenced their decision to have fetal surgery. Susan and Jim Johnson went through the fetal surgery program at Hilltop Hospital about four years ago and are now the parents of a little girl. They had a very positive experience, successful in that it resulted in the birth of a live baby, and they have spoken publicly about fetal surgery on many occasions. They are also quite firmly positioned on the anti-abortion side of the abortion wars and see fetal surgery as a useful tool in transforming political activism in this arena. Although certainly not representative of all or even most fetal surgery experiences, Susan and Jim's story provides a snapshot of how some of these issues are played out in the context of "real" people's lives.[7]

The Johnsons live in a fairly large city in the southern United States. Susan is in her late twenties, a big-boned, pretty woman with a mass of blond hair and a lot of energy. Mark, in his late thirties, has a receding hairline and the oratorical style of a fundamentalist preacher. They work in a family business and seem to enjoy a comfortable, middle-class lifestyle. Both are animated in conversation, sometimes talking over and around each other in order to make their points. The Johnsons are Reformed Episcopalians and adhere to a number of traditional, Southern Christian beliefs. They are Republican, anti-feminist, racist, anti-homosexual, opposed to gun control, opposed to abortion rights, and "pro-family"--in short, all the things one might expect of religious conservatives in the U.S. Originally from the Midwest, Susan seems quite strong-minded, although several times during our conversation I was struck by Mark's efforts to have the last word, so to speak.

The Johnsons already had two children, a five-year old boy and a 15-month old boy, when Susan became pregnant again in 1991. Initially thrilled about the

---

[7]This story is based on a number of data sources, including a focused, in-depth interview with Susan and Jim Johnson; magazine articles about the Johnsons; a 20/20 segment in which they were featured; and second-hand impressions from informants at Hilltop Hospital. I choose not to cite published sources here in order to protect the Johnsons' identities.

pregnancy, Susan was devastated to learn in the fourth month of pregnancy that her fetus had a tumor growing in its chest, crushing the heart and lungs. The condition, called congenital cystic adenomatoid malformation (C-CAM), is fatal if left untreated because it prevents vital organs from developing properly. Local doctors in their city felt there was nothing they could do. Desperate, Susan and Jim pursued other avenues and finally learned about experimental open fetal surgery at Hilltop Hospital. They contacted Drs. Graham and Murphy and forwarded their medical records for review, eventually gaining approval to journey to California for evaluation and possible treatment.

Susan and her fetus met Hilltop's selection criteria and underwent surgery shortly after arriving in California, at about 23 weeks gestation. As in all fetal surgery cases, preterm labor was a major concern both during and after the operation. Susan admits that surgery was "a very hard thing to do physically" and that she was "tapped out" often. Twelve days after surgery, Susan prematurely went into labor and her fetus was delivered by cesarean section. The newborn weighed less than two pounds and was immediately whisked off to the Neonatal Intensive Care Unit. After several rocky months of additional treatment and monitoring, including care for a collapsed lung and open heart surgery, the baby was well enough to leave Hilltop Hospital. Elizabeth Ann weighed just under four pounds when Susan and Jim brought her home.

Susan and Jim believe their daughter is a miracle baby, and they are fiercely proud of her. When describing their experiences with fetal surgery, they were both adamant about not referring to Elizabeth as a fetus, insisting on terms such as unborn child and unborn patient. They are vehemently opposed to abortion, which Susan characterized as "an act of convenience for some women." She remarked that "if women stop making decisions based on their own convenience then abortion might end." Having made such a sacrifice on behalf of her own daughter seemed to bolster Susan's belief that women who choose abortion are selfish. Jim described abortion as

murder, the killing of an unborn child, and became quite heated and passionate in his defense of the anti-abortion platform. At one point, he began pacing the floor, speaking faster and louder in his excitement and fervor about the absolute wrongness of abortion. They see Elizabeth, their "miracle baby," as living proof that a surgical intervention is preferable to abortion as a treatment option.

When I asked how Susan and Jim felt about fetal interventions in general, fully expecting a religious doctrine about letting nature take its course, Susan and Jim surprised me. They told me that "it is a form of human arrogance *not* to take advantage of the technology that God has given us. Medicine and science are gifts of God, designed to make our lives better and to create miracles." The Johnsons are thus quite eager to support the enterprise of fetal surgery, and are enthusiastic about any scientific or medical practice which fosters the notion of the unborn patient. They have started a private philanthropy, named after their daughter, to support the work of the fetal surgery team at Hilltop Hospital. They hope to raise enough money through their vast network of anti-abortion connections, as well as through family ties, to seed a substantial funding base.

Their insight into how the foundation might fit into the anti-abortion movement was both sophisticated and startling. The Johnsons feel that traditional pro-life politics are virtually bankrupt. Jim pointed out that the specter of RU486, which would provide non-surgical abortions earlier and at any medical site rather than clinics only, threatens to render images of so-called aborted fetuses less effective in the political realm. He and Susan both feel that emphasizing "fetal patienthood" is a better way to assert "fetal personhood," and they used these very terms to describe this. They are enthusiastic about any practice which will facilitate constructions of fetuses as unborn patients, unborn children, persons, and other human identities. In this regard, their positive experience with fetal surgery sustains and invigorates their political views and activities. They believe that a "legitimate, scientific foundation, not directly linked

to the anti-abortion movement except through funding, advice, and support" will be critical to the future of anti-abortion politics. Ironically, they hope to portray their foundation as a "non-political" organization, although they have numerous informal connections to the anti-abortion movement.

As one might expect given controversy surrounding fetal research, overtly linking fetal surgery with abortion politics makes the fetal surgery team at Hilltop Hospital squirm in discomfort. The fetal surgeons are nervous about Susan and Jim Johnson, even while they welcome the financial support the Johnsons hope to provide. When they learned that I would be interviewing the Johnsons, the fetal surgeons carefully pointed out that Susan and Jim are not representative of all fetal surgery patients. Dr. Graham told me that although most patients tend to be opposed to abortion, not all share the "extreme views" of the Johnsons. Peter Quinn, a consultant to the Fetal Treatment Unit, suggested that I contact a couple in Seattle who are "much less political" in order to get a balanced view. The methodological issues raised by these warnings are not insignificant and I have clearly argued here that all patients are *not* like Susan Johnson. But it is obvious that the fetal surgeons' anxiety about the Johnsons is grounded in political, rather than methodological, concerns. The fetal surgery team strives to downplay the political nature of fetal surgery, recognizing that controversy poses a threat to the longevity of their work. As Dr. Nelson astutely pointed out, "The only issue now, the biggest fly in the ointment, is political. If we are squelched at Hilltop Hospital, it will be for purely political reasons."

With patients like Susan Johnson serving as potent reminders, medical workers clearly recognize that reproductive politics and beliefs undergird women's choices in fetal surgery. Yet for them, sorting out all the implications and factors is a complex undertaking. Dr. Hansen summed up some of the issues nicely: "You know, it's an incredible commitment that the parents, particularly the mother, makes with this intervention. Because she has a big operation, because the medicines we give

her to prevent labor maker her absolutely miserable. And it's an incredible sacrifice. We try to let them know that pre-operatively, and so I think that an easier option would be to opt for abortion. And I think by the nature of that, the women tend to be less pro-choice. But at the same time, our philosophy is that if we really cannot fix the problem, then we do a fetectomy, we take the fetus out. I suppose there are a lot of real ardent anti-abortion camps out there who would probably feel that we shouldn't do any intervention on the fetus...I think it could potentially become a real hot spot in the abortion debate."

Because reproductive beliefs are so deeply held by people, women's politics and medical workers' politics sometimes clash in fetal surgery. Dr. Nelson outlined some of the ethical and legal challenges posed by fetal surgery: "Biologically we're treating the fetus as a patient, as part of mom, and it's a patient because mom says it's a patient. If she says it's not a patient, it's not a patient. The legal framework is that it could still be aborted. I think more than anything else it shows how artificial the framework is. But it never happens. And the reason it never happens is that mom has never decided to make it an abortion. Mom still has a say." I asked Dr. Nelson what would happen if one of the women did choose to have an abortion following fetal surgery. He replied, "Who decides to abort? It's her decision." I pushed a bit harder and asked him how he would *feel* about it. He admitted, "I would be upset, mostly because we'd have invested time, energy, effort in the fetus' well-being. And I would feel that mom's shortsightedness had really ripped off that fetus, as well as our investment of time. It would be a terrible thing. The truth is it will probably never happen because these moms are just fantastic. The moms who decide to do this are in every way heroic. I mean, they are truly heroes."

Dr. Nelson's use of the term "heroes" to describe the pregnant women, although heartfelt, is somewhat problematic. In exalting women who choose fetal surgery, acceptance of surgical intervention is seen as something to be rewarded. Yet

the many women who opt to forego fetal surgery in favor of a different treatment or who choose to abort their fetuses are faced with decisions every bit as daunting and complex as Susan Johnson's. Such decisions, regardless of their ultimate outcome, are fraught with ambiguity and may require considerable emotion work (Hochschild 1983). It seems unnecessary to define the pregnant women in fetal surgery as heroes in order to appreciate their commitments and the work they do. The women in fetal surgery are neither more nor less heroic than any other woman making a difficult reproductive choice within the current zeitgeist of the abortion wars. Regardless of their particular treatment trajectory, what all these pregnant women share is a commitment to saving their babies and a willingness to invest an extraordinary amount of time and effort in doing so.

"I Had No Idea It Would Be Like This": Women's Organizational and Body Work in Fetal Surgery

A consistent theme in this dissertation has been the medical work that undergirds the emergent specialty of fetal surgery. Focused on the fetal patient, the primary work object, the fetal surgery team engages in a number of practices designed to save babies. Pregnant women often are configured as support technologies or technomoms, "the best heart-lung machine available." Yet in attempting to understand women's roles in fetal surgery, it is crucial to focus on the organizational and body work that they do in this domain. Not only are they engaged subjects whose choices and politics shape their participation, they also work to manage and negotiate the major disruptions in their lives and bodies that result from fetal surgery.[8] Although methodological constraints prevented a full examination of women's work, especially their emotion work (Hochschild 1983), the following illustrates certain aspects of their role as engaged workers in this specialty. As one patient, Kelly,

---

[8]See Strauss et al. (1982) for a discussion of the work that hospitalized patients do.

stated, "I had no idea it would be like this." Focusing on women's organizational and body work provides one avenue for making sense of this candid admission.

To choose fetal surgery as a treatment option, pregnant women usually must profoundly reorganize their lives. Because fetal surgery is experimental and offered at only a handful of facilities in the U.S., what I am calling *organizational work* involves travel, large time commitments, living in a different city for several weeks, financial expenditures, and even leaving other family members behind. In the patient education video, women are told they must expect to remain near Hilltop Hospital for the duration of their pregnancies, sometimes up to two or three months. They are also told to make financial arrangements prior to traveling to determine their eligibility and coverage. In addition to these concerns, pregnant women must also cope with being bedridden immediately after surgery. To prevent premature labor, they are discouraged from moving around. Boredom and frustration become real problems for these women. All of these factors take a considerable toll on both the pregnant women and their partners and families. Social worker Barbara Greenwood told me, "It takes a certain kind of person to do it. I still find it fascinating to see people make these kinds of sacrifices, even in the face of statistics that are not at all reassuring." It is these kinds of commitments, in addition to women's decisions to pursue fetal surgery, which define them as "heroes" in the eyes of fetal surgeons.

Dr. Hansen discussed some other aspects of women's organizational work: "It's an incredible commitment the mother makes with this intervention...There are an incredible number of medical bills. Usually what has to happen is the mother has to stay out of work. It disrupts everything in the family." Susan Johnson is a good example of this. She told me how hard it was for her to spend several weeks at and near Hilltop Hospital, far away from home. Although her husband, Jim, joined her for most of the post-operative period, she had to leave her other two children at home in a relative's care. Her youngest son was only 18 months at the time, and she found

leaving him to be very difficult. Often such hard choices are made bearable only by the support of the patient's partner. Another patient, Marla, talked about how important it was to her to have her husband, Dan, at her side the whole time. Marla stated, "It would have been impossible without him."

In addition to the organizational work that women do, they also engage in significant body work in the pursuit of healthy babies. Here I am defining body work as labor related to corporeal or physical characteristics and activities. I use it in the dual sense of women's own physical labor, as well as work done on their bodies by other people. From the moment a pregnant woman learns that her fetus is sick until she makes a treatment decision, organizational and body work intermesh as the woman considers her options and reorganizes her life to pursue them. Several cases illustrate how complicated this process can be. Amber, whose 28-week fetus was diagnosed with polyhydramnios, was referred for treatment after having amniocentesis at her local hospital. After having this diagnosis confirmed at Hilltop, she was asked to return one week later for follow-up. Beatrice, a 17-year old from southern California, was referred with fetal encephaly, or bowel loops in the amniotic space. She underwent prenatal diagnosis at Hilltop Hospital, which revealed normal chromosomes and hydronephrosis (swelling of the kidneys resulting from obstructed urine flow) in her fetus. One month later she returned for follow-up diagnosis, which determined that the hydronephrosis had worsened.

Not all of the women diagnosed with sick babies who come to Hilltop opt for fetal surgery, but the routes they travel in making some kind of treatment decision are decidedly laborious. In addition to criss-crossing the United States seeking medical advice and diagnosis, they also must incorporate diagnostic and treatment information into the contexts of their lives. Whether the women chose fetal surgery, abortion, or some other kind of fetal treatment, or decide to do nothing, the very fabric of their lives is inextricably reorganized in line with their decisions. While they may be "heroes"

who sacrifice a great deal for their fetuses, they are also ordinary women attempting to cope with a serious medical problem. One 19-year old patient's story, told by one of the social workers, illustrates the complexity of the women's lives. Shortly after her operation and needing some kind of break from the intensity of fetal surgery, April Saunders went to Great America with her sister, prompting considerable outrage by her doctors. Lucy O'Neill told me, "So she went ahead and went to Great America, her sister took her. You know, she's wearing a terbutaline pump; it was madness." Terbutaline is a tocolytic agent to prevent preterm labor; it may be administered intravenously or subcutaneously from a pump attached to a woman's body (Scheerer and Katz 1991). April's story inspires because it illustrates that, although these women work hard to save their babies, they do so within the broader framework of who they are and what they are willing and able to do on behalf of their fetuses. It also shows that these women struggle to maintain many aspects of their identities across sites, suggesting that they perform identity work as well.

Earlier we heard from some of the patients about how physically demanding, painful, and arduous fetal surgery can be for the pregnant women. As a way of showing how body work is required of women who undergo fetal surgery, I next describe several cases in detail. The first illustrates how significant corporeal issues are to decisions *about* fetal surgery. During a fetal treatment meeting, medical staff discussed a potential patient, Tina, whose fetus was diagnosed with a left-sided diaphragmatic hernia. Tina had previously given birth to a baby with hypoplasia, a condition in which tissues and organs do not not adequately develop, and had already had three cesarean sections. She was described as heavy and tall, prompting those present to identify her as a poor risk for fetal surgery. This spurred a discussion of April Saunders, who is 5'9" and weighs 210 pounds. Dr. Graham remarked that he "hadn't appreciated her size" at the time of her surgery. Somebody else commented that her weight "probably isn't being helped by all the McDonald's she's eating now."

Given that April is a young woman on public assistance, the class dimensions of these comments are striking. These discussions illustrate the importance ascribed to corporeal *and* social characteristics in fetal surgery.

Prior to surgery, pregnant women who come to Hilltop Hospital must often engage in body work related to prenatal diagnosis. For example, Meredith was referred to Hilltop Hospital from the Mayo Clinic with twin fetuses, one healthy and the other with a hollow ventricle in its head. She wanted to have the sick fetus "selectively terminated," or aborted. Dr. Siegel, and obstetrician, and Dr. Simmons, a sonographer, found the case "fascinating" because the fetuses were in unusual positions. Simmons stated, "In order to get a successful sonogram, ultrasound had to be done at a really strange angle to get at the second twin. Walter [Siegel] had to get at the abnormal fetus in this weird way. It was difficult but he did it." This case prompted a discussion of different kinds of ultrasound, with Siegel remarking that transcervical or transvaginal ultrasound poses "a greater risk of infection and it hurts more." For Meredith, obtaining a diagnosis and treatment for her fetus meant presenting her body for technological manipulation.

Body work is especially evident in the operating room. As discussed in earlier chapters, fetal surgery requires a number of complex, delicate, microscopic manipulations in pregnant women's bodies. Since I have quoted at length from my observations in other chapters, consider the following published account of maternal body work in fetal surgery:

> "Maternal preparation begins with a 100-mg suppository of indomethacin before operation and placement of an epidural catheter for postoperative analgesis...Maternal intraoperative monitoring includes a blood pressure cuff, large-bore intravenous catheters, a bladder catheter, electrocardiographic leads, and a transcutaneous pulse oximeter...The mother is positioned supine

> with towels placed under the right side to lift her uterus off of the inferior cava to avoid compromise of venous return. The uterus is exposed through a low transverse abdominal incision and delivered into the operative field. A large abdominal ring retractor is used to maintain exposure...The position and orientation of the hysterotomy is planned to stay as far away from the placenta as possible and still allow exposure of the appropriate part of the fetus...An alternative method to minimize blood loss during hysterotomy is manual compression on either side of the proposed hysterotomy...Immediately thereafter specially designed compression clamps are placed around the edge of the uterine incision to prevent bleeding" (Harrison and Adzick 1991:287-288).

This passage illustrates the extraordinary physical manipulations required in surgery, and the body work performed on women by fetal surgeons attempting to access the fetal patients.

Tocolysis is especially important both during and after surgery, and it is required for all patients undergoing hysterotomy for fetal manipulations. As Scheerer and Katz (1991:182) state, "Tocolysis for fetal surgery provides the quiet and relaxed uterus necessary during surgical manipulation...The induction of preterm labor is the most feared complication of fetal intervention. Among 28 open procedures performed in the nonhuman primate, preterm labor developed in 38% of monkeys who underwent hysterotomy without fetal surgery and in 55% of monkeys who had both hysterotomy and fetal surgery." The authors go on to describe a number of different tocolytic agents and how they work in pregnant women's bodies. These agents are divided into two categories based on their method of action. One category contains agents which alter the response of the myometrium (muscular wall of the uterus) to stimulation, and

the other category of drugs blocks or suppresses the release of recognized myometrial stimulants. Among the different tocolytic agents in the first category are ß-mimetic agents (ritodrine, terbutaline), magnesium sulfate, calcium channel blockers (nifedipine), and progesterone. In the second category, agents include prostaglandin inhibitors (indomethacin), ethanol, and oxytocin or vasopressin analogs. Maternal complications from these drugs, not all of which are currently in use, may include pulmonary edema, cardiac arrhythmia, myocardial ischemia, hypotension (reduced blood pressure), altered metabolism, decreased muscle tone, respiratory problems, nausea, vomiting, dyspepsia, and cardiac arrest (Scheerer and Katz 1991). In fetuses and newborns, terbutaline may lead to higher rates of tachycardia (rapid heartbeat), magnesium sulfate may lead to neuromuscular depression, and indomethacin may lead to cardiovascular and renal problems (Scheerer and Katz 1991).

Tocolysis is important in the postoperative period, as well. Here women must do a significant amount of body work as they recover from surgery and prepare for birth. They learn to monitor their contractions, administer tocolytic drugs daily, commit to continuous bed-rest, and take care of themselves as embodied patients in different ways. Dr. Graham remarked, "Keeping the kid inside until he's big enough and ripe enough to come out and be a good kid--that's a struggle. A guaranteed struggle for the mom." Dr. Amos described the first few days after surgery as the hardest: "They've been bombarded with medications, bombarded with general anesthesia, they've had an incision in the uterus, and they're *still* pregnant." One patient, Wendy, described her post-operative experiences: "I was using the morphine button because they give you a button to control it. I guess I pushed it like 15 times in an hour." And Barbara Greenwood talked about the preterm labor problem: "[April] finally did go into preterm labor at about 30 weeks, which seemed unnecessary at the time, although in retrospect it seems as if everybody goes into early labor. So maybe it was about April and maybe it was about just what this is."

In sum, as participants in fetal surgery pregnant women must engage in a considerable amount of organizational and body work. This may range from traveling great distances to having their bodies worked on during surgery to actively working to prevent preterm labor in the post-operative period. Like the fetal surgery team, pregnant women are focused on saving their babies and are committed to the needs of *their* fetal patient. Yet, while pregnant women's bodies undergo a great deal of manipulation by others during fetal surgery, viewing this as a form of organizational or body work positions women as engaged participants and allows us to see fetal surgery more clearly as a women's health issue. It is important to focus on women's participation as active workers in order to offset the notion of pregnant women as merely passive work objects or technomoms. It recognizes their subjectivity in choosing to be technomoms even while acknowledging that body work can be both active and passive. Next I address constructions of maternal risk in fetal surgery, another site where women's work is significant as they assume high levels of risk on behalf of their fetuses.

"We Haven't Lost a Mom Yet": Constructions and Assumptions of Maternal Risk in Fetal Surgery

Experimental fetal surgery is a risky business, particularly for the pregnant women who undergo it on behalf of their fetuses. All participants acknowledge that maternal risk and safety issues are paramount in fetal surgery, with fetal surgeons proudly stating "We haven't lost a mom yet." Risk is important for several reasons, the most significant being that if a pregnant woman were to die during fetal surgery, it is likely the practice could not continue. The longevity of fetal surgery as a new and experimental clinical specialty rests on its establishing satisfactory levels of maternal risk. In a risk-benefit analysis applied to fetal surgery, some maternal morbidity may be considered acceptable by some practitioners but maternal mortality is clearly not

acceptable, at least for oversight committees, funders, and many of the medical workers. As other practitioners point out, given that there is *no* clinical benefit for pregnant women *at all*, even some maternal morbidity may be too great a risk. Yet somewhere between death and safety is an ambiguous gray zone, where medical workers in fetal surgery define risk through their everyday practices of operating on pregnant women and fetuses and where some pregnant women accept risk as part of their commitments to saving their babies. As Moore (1996) has argued in relation to safer sex technologies, there is no standard meaning of acceptable risk. The same can be said of experimental fetal surgery.

Risk and safety are defined in a number of ways in the clinical literature and by fetal surgery participants. Harrison and Adzick (1991:287), for example, have asserted that "maternal safety is the paramount consideration in fetal surgery." Maternal risk is dimensionalized across four different categories: operative technique, postoperative management, maternal outcome, and future reproductive potential. Based on animal and human experimentation, a number of perioperative practices are claimed to minimize risk, including a range of management and monitoring strategies. In the postoperative period, premature labor is the largest obstacle to successful outcomes and is increasingly managed by a regimen of tocolysis. Of greater concern with respect to risk are maternal outcomes and future reproductive potential. Between 1981 and 1989, 18 women underwent fetal surgery at Hilltop Hospital (Harrison and Adzick 1991). Fifteen of the operations resulted in a live fetus; in three cases, the fetuses were removed during surgery. Harrison and Adzick (1991:289) write, "Obviously maternal safety is the first priority in all cases. There have been no maternal deaths and few maternal complications." He goes on, however, to describe several problems that have come up, including pseudomembranous colitis, an amniotic fluid leak, and maternal mirror syndrome. One case in which a woman went into premature labor and delivered vaginally is chalked up to "poor patient compliance"

(1991:289), although it is not clear why this case is considered clinically problematic as there is no evidence that the fetus died.

Harrison and Longaker (1991) discuss maternal risk in the context of the development of fetal surgery as specialty. They first describe ten years' of animal experimentation in over 200 monkeys as a way of legitimating their efforts in humans (See Chapter 4). These experiments were seen as necessary because fetal surgery "can be justified only if the risk to the mother's health and reproductive potential is acceptable. The main deterrent to direct fetal intervention by hysterotomy is not the risk to the fetus (who will benefit if the intervention is successful) but the risk to the mother" (Harrison and Longaker 1991:189). Maternal morbidity in fetal surgery is roughly equated with other cesarean sections, "except for the ongoing problem of a continuing gestation (e.g., preterm labor) after surgery" (Harrison and Longaker 1991:199). Among the complications which occurred in a sample of 13 women between 1981 and 1989 were amniotic fluid leaks, premature rupture of membranes, chorioamnionitis requiring a cesarean section, enterocolitis, hyperplacentation syndrome, pulmonary edema, persistent oligohydramnios, and premature labor (Harrison and Longaker 1991:200).[9] Despite these risky consequences of fetal surgery, the authors state "Obviously, maternal safety is the first priority in all cases. Fortunately, there has been no maternal mortality, and significant morbidity has occurred in only one case" (Harrison and Longaker 1991:199). Clearly, risk is

---

[9]Harrison and Adzick (1991) report that 18 women underwent fetal surgery between 1981 and 1989, whereas Harrison and Longaker here report 13 women during the same period. The source of the discrepancy is not addressed, although the latter account excludes C-CAM cases whereas the former account does not. During an interview with fetal surgeon Tony Murphy, I was told to be careful about how I cited fetal surgery cases. He stated, "We only talk about patients that we have published. And that should go for your dissertation as well, or in the press. Because we like things to be peer-reviewed before we talk about them. So we only discuss things that are published. There have been two sacrococcygeal teratomas, eight cystic adenomatoid malformations, seven or eight urinary tract vesicostomies, and about 20 published diaphragmatic hernias. So you can add them up. We've done more, but there's always a lag between when you do something and when you write it up...So we don't want your dissertation to compromise our publication because it's work from our group. Is that fair?"

minimized in this published account and morbidity is defined to exclude the complications discussed earlier.

Future reproductive potential, defined as the ability of the woman to carry further pregnancies, is an issue of concern in all accounts of maternal risk. Minimal adverse effects have been found on future reproductive potential, although all women who experience fetal surgery are committed to cesarean section for any subsequent pregnancies. Initially evaluated in nonhuman primates, reproductive potential was recorded in a large computer database at a nearby Primate Research Center (Harrison and Adzick 1991). This database provided information about subsequent breeding and permitted comparison of the primate group with the experimental fetal surgery program at Hilltop Hospital. In animals with absorbable uterine sutures, fetal surgery did not affect subsequent fertility; however, where metal staples were used fertility was markedly compromised. Further, uterine rupture occurred in five of the nonhuman primate cases, while 62 primates delivered vaginally without complication. Of the 18 human patients operated on between 1981 and 1989, seven had subsequent pregnancies and deliveries by cesarean section with "good outcomes" (Harrison and Adzick 1991). The other patients were still too close to their operative dates to assess subsequent fertility, making follow-up more difficult. Since 1989, there have been approximately 25 additional patients operated on at Hilltop Hospital. To date, no *long-term* outcome studies have been published in which human fetal surgery patients are assessed for subsequent reproductive potential or for other health problems which might be sequelae to the fetal surgeries and postoperative care.[10]

Given the carefully articulated discussions of risk in the clinical literature, it is comparatively useful to examine how participants in fetal surgery talk about maternal

---

[10]Fetal surgery raises a number of important issues for women's health beyond the operating room. Possible sequelae include consequences of multiple cesarean sections such as back problems due to abdominal weakness, the possibility of uterine rupture, loss of reproductive potential, urinary impairment from sustained catheterization and/or injury, circulatory problems, long-term effects of tocolytic agents, muscle loss due to immobility, and a range of other problems that have not been investigated in humans.

risk and safety. As the following data illustrate, the language of risk permeates experimental fetal surgery. Jack Nelson told me, "Mom deserves the very best in monitoring and treatment to optimize her outcomes and to minimize her risk." He went on to describe the women as "willing to risk it all" in "the most complex operation that's being currently undertaken." In describing the early successes and failures of the program at Hilltop Hospital, Nelson was quick to point out, "No moms have ever been injured, though we had some fetal deaths." In discussing mismanagement of cases by obstetricians, he remarked that "they put mom and fetus at great risk...But there is much that can be done to improve mom's care, decrease her risk, and improve the outcome of the fetus." When I asked him about ethical issues in fetal surgery, Nelson told me, "The overriding number one concern is to maintain mother's health. That is, without question, number one in everybody's mind. All the friction comes about *how* to obtain that."

The "friction" Nelson refers to concerns multiple definitions of risk and safety, as well as differences among participants about what constitutes an acceptable level of risk. As with other issues in fetal surgery, obstetricians are perhaps the most vocal objectors to *any* level of maternal morbidity and mortality. Recall from the previous chapter Dr. Siegel's dissatisfaction with diaphragmatic hernia cases and "the problems that have never been solved." There are also differences surrounding how new experimental practices should be introduced, with Dr. Siegel believing that some procedures are "not fair to the patient." Yet like Harrison and Longaker (1991), Siegel agrees that animal experimentation can help to minimize risk in humans. He told me, "Those are dues that have to be paid. You have to get that animal data if you're going to start with any reasonable safety in human work that is at all interventional in nature." Overall, Siegel defines fetal surgery as "too risky," with limited benefits not worth the cost to pregnant women's health.

Barbara Greenwood, a social worker, has a somewhat different construction of maternal safety and risk in fetal surgery. She told me, "I wasn't as concerned about the mothers dying because I've come to realize that we know enough about maternal care here and we just won't let them die. But we almost lost a patient, a woman who I got to know very well. We held her baby when it died...and it was a very tumultuous and difficult case." In describing risk, she stated, "Even if the surgery is perfect, all of the things we have to do to keep a baby inside a mother who's postoperative and in preterm labor complicates the course for the mom and her baby." Greenwood also worries about other risk factors, particularly reproductive potential. She told me, "The other big dilemma for me are these young moms. It's one thing when you're 36 and you've been trying for 15 years to be pregnant, and this is your last shot...But when you're 17 years old, or 18 or 19, you have a long future of fertility ahead of you. And what we're doing is putting these people at risk for complications, and at the very least for the necessity of having cesarean sections later. Is that reasonable?...At some point we need to look at an age cutoff. Which women are we in good conscience putting at risk here?"

Greenwood raises an important issue, because the assumption of risk and surrender of safety in fetal surgery constitute a form of work by pregnant women and an investment in these fetuses. Accepting a certain degree of risk on behalf of their fetuses renders these pregnant women "heroes" in the eyes of medical workers. As the data from the first part of this chapter illustrate, pregnant women undergo extraordinary physical discomforts and risks in order to save their babies. In this sense, fetal surgery may be considered a public health issue despite the relatively small number of women who have been operated on. For example, Paula Jones, Director of Community Services for a local chapter of the March of Dimes Birth Defects Foundation, told me that fetal surgery is a challenging issue with respect to maternal risk and safety. Drawing on her background in public and community health,

Paula articulated her own concerns about an experimental practice with questionable benefit to fetuses and clear risks to maternal health and well-being. Given that the mission of the March of Dimes is to improve the health of babies, fetal surgery is considered worthy of financial support and is a frequent recipient of foundation grants. Yet because it poses significant risks to pregnant women, also of great concern to the March of Dimes, it becomes problematic from an epidemiological perspective and may well be considered "a public health issue."

Social commentators, actors outside the medical domain per se, have also identified risks in fetal surgery and questioned the viability of treatments focused on the fetal patient. Their emphasis is often quite different from that of medical workers. For example, Kaufmann and Williams (1985:27) write, "Fetal surgery brings this issue into sharp focus, since access to the unborn child is possible only through invasive procedures applied to the mother's body...The decision to initiate treatment must be made with equal attention to preserving and enhancing the well-being of both the mother and the live fetus she carries." For these authors, risk is something to be calculated by physicians as they make complicated treatment decisions. They point out that "treatment of the fetus must be considered in the context of the continued health and well-being of the mother." Ironically, and somewhat erroneously as the above data illustrate, Kaufmann and Williams place most of the *medical* risk with the fetus, as it is the target of intervention and treatment. In their view, maternal risks are largely *legal*, particularly in cases where pregnant women may disagree with their physicians about treatment. They point out that there is a legal precedent for overriding women's refusals of cesarean sections in favor of fetal interests. Although most women are engaged in fetal surgery and want to do anything they can to help save their babies, Kaufmann and Williams raise the possibility of court-ordered fetal surgery further downstream should women and their doctors disagree. For these

authors, then, maternal risk has more to do with the social implications of fetal surgery than with immediate clinical threats to women's safety and well-being.

In sum, then, fetal surgery is ripe for fresh consideration of *maternal* risk and safety issues. As a practice geared toward the fetal patient, pregnant women's participation is often seen as peripheral. Maternal morbidity and mortality are defined as important issues by participants, but often for a variety of different reasons. For pregnant women, who benefit only indirectly from fetal surgery with the possibility of a reasonably healthy baby, a certain amount of risk is worth assuming. The women who talked about fetal surgery as "worth the effort" make their own complex analyses. They may well *not* have considered "costs" and "benefits." For their part, fetal surgeons and obstetricians attempt to minimize maternal risk and prevent pregnant women's deaths. For obstetricians, this is related to their professional concern with maternal health and is often presented as a counter to the aims of the fetal surgery team. For fetal surgeons, minimizing risk has to do not only with concern for moms and fetuses, but also with the continued longevity of the fetal surgery program at Hilltop Hospital. Because fetal surgery is experimental and pregnant women participate on behalf of their fetuses, "losing a mom" would pose a serious threat to the specialty's continuance. As Dr. Graham states in a patient education video, "Risks to mom are real...to the extent that this a real operation like a cesarean section....But a cesarean section with a difference." It is this crucial difference which is the focus of the next section.

One Patient or Two?: Some Tensions "Embodied" In Experimental Fetal Surgery

Contrary to pregnant women's engaged participation in fetal surgery, the pervasiveness of a discourse of maternal/fetal conflict in medicine, law, ethics, and reproductive politics is striking (Casper 1993). Among non-feminist ethicists, for

example, the difference between a fetus and a newborn is often construed as "merely geographic." As Sherwin (1992:106) argues, the only way in which this framing makes sense is if pregnant women are conceptually erased from the experience of pregnancy, or reduced to a flesh and muscle barrier separating "fetus fixers" from their patients.[11] Yet despite the ubiquitous assumption that a pregnant woman and her fetus are distinct entities with different interests and needs, the embodied nature of pregnancy and the maternal/fetal relationship tends to obviate this discourse. As fetal surgeons discovered when they attempted to access their primary patient, the "merely geographic" barrier blossomed into a living, embodied, social, cultural, political, scientific, and clinical barrier. Dr. Hansen, a surgical resident, summed up the tensions nicely: "You basically have a mother who's healthy and a fetus who's sick. In order to get at the fetus, you have to go through the mother which presents potential for harm to the mother. So we need to develop safe ways of getting to the fetus." The necessity of having to "go through" women meant that surgeons were *forced* to recognize that "there's an additional player involved, and that's the mom," as Dr. Murphy phrased it. Pregnant women are "additional players" both as engaged subjects invested in their fetuses and as clinical work objects. Next I examine some ways in which these tensions unfolded in the fetal surgery unit at Hilltop Hospital, illustrating how the maternal/fetal conflict paradigm is simultaneously sustained and challenged through these practices.

---

[11]The term "fetus fixers" comes from a plaque in one of the Fetal Treatment Unit's offices. It was hanging alongside another plaque reading, "Womb With a View."

"Optimizing Mom to Save Her Fetus": Strategies for Managing the Maternal Work Object

Dr. Graham remarked once in a meeting that "when we do our thing it's all or nothing. We don't pull out live babies."[12] The blunt significance of this sentiment and other types of investments in fetal surgery suggest that the fetuses which survive a harrowing operation become quite valuable to those who are trying to save them. Extraordinary measures are often taken to ensure that a successful operation, one in which the fetus lives, is followed by a successful post-operative period with continued fetal and maternal survival. According to Dr. Murphy, "The advantage [of fetal surgery] is that the mom's brought in and, under controlled circumstances, the baby is cared for." Dr. Nelson remarked, "Mom deserves the very best...to try to save the fetus. In order to do that we have to optimize mom." In short, surgeons attempt to manage as many aspects of fetal surgery as possible, rendering both pregnant women and their fetuses work objects beyond the walls of the operating room.

Fetal management strategies are consistent with a surgical approach focused on the fetal patient. Every effort is made to ensure that fetuses survive surgery and live through the post-operative period until birth by cesarean section. Surgeons assiduously pursue techniques and practices which will accomplish this, often referring to them in terms of fetal management. For example, at one meeting a suggestion was made that sonograms be done post-operatively in order to diagnose problems and avoid fetal death. In concurring, a sonographer remarked, "We also need to incorporate echo[cardiogram]s into fetal management." Dr. Graham, in discussing functional assessment of fetuses after birth, remarked, "We're getting worried about

---

[12]Harrison and Adzick (1991:288) have written, "As a general principle, fetal surgery should be 'all or none,' i.e., the fetal repair should be complete and adequate to ensure a good chance for fetal survival, or else the otherwise doomed fetus should be removed. A partial or inadequate repair presents an ongoing threat to the mother for little potential benefit." A similar sentiment was expressed by Dr. Steven Ringer in a recent popular article (Frey 1995:25) on the harsh realities and ethical dilemmas of neonatal treatment of very premature babies. He remarked, "The essence of intensive care medicine is, you have to take risks...Kill 'em or cure 'em. But don't screw around."

things that happen outside the uterus that don't happen inside the uterus. We need better management so that pediatricians are ready for these kids immediately at birth." Thus, not only is management necessary during and immediately after surgery, it may also facilitate neonatal care further downstream.

Yet in addition to an emphasis on fetal management, the language of fetal surgeons and other clinical staff is rife with metaphors of *maternal* management. They routinely talk about "managing mom in an intensive setting" or "optimizing mom to save her fetus." Often discussions of management occur alongside evaluations of success or failure in fetal surgery. Management becomes an especially acute issue after fetal deaths or when there are significant problems with a case. For example, a special meeting on fetal management focused on monitoring was convened after a rash of fetal deaths occurred in the post-operative period. In suggesting that I attend this meeting, one of the nurses, Tracy Knox, told me that I might not understand everything that was said, but that "the politics should be interesting." During the meeting, Dr. Graham referred to the diverse group of specialists in the room--including obstetricians, sonographers, physiologists, and others--as "a special working group to address the problems of post-op management." He remarked that survival statistics are "so far two out of three," and "what is needed is a strategy for increasing management." Discussion during this meeting focused on ways of achieving this goal.

In clinical practice, surgeons have been especially frustrated with the dilemmas of post-operative care. Dr. Nelson told me, "We don't lose fetuses during an operation...Now we're dealing with perioperative mortality." Their concerns stem from what happens to fetal work objects when they are replaced in the uterus and thus removed from surgeons' direct purview. Many fetuses which die do so in the post-operative period, even after a "successful" surgery. Dr. Nelson reported that the team had "a bunch of deaths in the first 24 hours, we call mysterious deaths." And Dr. Murphy lamented that "it's very frustrating to do your best work and then lost the

baby post-op. It makes one wonder if it's okay post-op to put the baby back in and assume that mom will take care of things."[13] This comment is telling, for it illustrates not only surgeons mistrust of pregnant women's bodies but also the material realities of pregnancy which constrains their work. It also reveals a discourse of blame and shifting accountability for problems which we saw in Chapter 5. Having done their "best work" during surgery, fetal surgeons are reluctant to relinquish control of their work objects back into what they are now constructing as a potentially dangerous environment. Yet they must do so because the uterus is recognized as a better (and cheaper) "recovery room" than the Neonatal Intensive Care Unit, particularly for very young fetuses which are not yet viable.

In managing the fetal patient, then, surgeons also strive to manage "mom" in as many ways as possible. One case in particular illustrates some of the problems that the fetal surgery team faces and their practical solutions. A 26-week old fetus with a right-sided diaphragmatic hernia survived surgery and then died post-operatively. According to Dr. Nelson, "the bottom line is that the operation was perfect and there was no identifiable cause of death." Dr. Graham concurred, stating emphatically that this was "the first mother that was satisfactorily monitored during surgery." Yet he went on to say that during the operation she experienced three uterine contractions on the operating table, causing surgeons to worry about "the effects on the fetus of controlling her" and suggesting that the operation was less than perfect. In summing up lessons learned from this case, Dr. Graham emphasized that "we need to increase management of mom." He called for additional monitoring, particularly in the post-operative period, stating that "the issue is to monitor the uterus post-op where the kid's inside. We're not very good at it." When some obstetricians in the room reacted negatively to this statement, Dr. Graham attempted

---

[13]A similar comment was made by Dr. Nelson in describing how the fetal surgery team evaluated a particular case after the fetus died. He stated, "We learned the value of an intensive care setting, that we had to optimize mom in order to make sure that it wasn't mom causing this fetus to die."

to placate them by saying "there is a terrible balance between care of the fetus and concern for the mother...But we don't monitor very well; we put the fetus back in and need to monitor more closely." As articulated by these surgeons, better management can only be accomplished through intensified surveillance of the pregnant woman and her fetus.

At this particular meeting, some examples of "better" monitoring already in use were discussed, such as ultrasound both during and after surgery and a radio telemetric device that keeps track of the fetal heart rate during surgery. Dr. Nelson, whose primary responsibility in the laboratory is to develop monitoring technologies, also described a new experimental technique which embodies some of the tensions in fetal surgery between fetal and maternal management strategies. Not yet used for humans, the technique was tried first in sheep and monkeys. It works by penetrating the placental vessel with a 22-gauge catheter which "comes out and gets hooked into the mother's body under the abdominal skin. If you want to access the fetus, you put a needle into the catheter through the woman's abdomen." Because the catheter is designed to remain in place in the woman's body, it provides an easy, accessible channel through which to diagnose, monitor, and even treat the fetus.[14] Dr. Graham described the technique as "the wave of the future," but asked others at the meeting "if it is worth the risk right now." Risk, in this case, is to the mother.

In addition to monitoring, another important aspect of maternal management is the administration of tocolysis to prevent preterm labor. A tocolytic is any agent which prevents or stops uterine contractions. Managing preterm labor occupies a significant amount of the surgeons' time, as they perceive it as their most challenging and potentially damaging problem. In primates, the "natural" tendency for a surgically breached uterus is onset of labor. Uterine contractions during surgery are caused by

---

[14]This is similar to the semi-permanent catheters, such as Swan-Ganz lines, used in cancer patients to introduce chemotherapy and other fluids into the bloodstream. These lines are often located in the chest and stay in place during treatment regimens, providing a stable channel while offsetting the need to gain intravenous access anew over and over again.

"making a big cut in the uterus," as Dr. Murphy put it. Because most fetuses are operated on at an early gestational age, success is contingent on being able to put the fetus back into the uterus for further growth and development. A contracting uterus is not a suitable place for a fetus and generally signals the end of a pregnancy. For fetal surgeons, "premature labor remains the largest obstacle to a successful outcome in the postoperative course" (Harrison and Adzick 1991:288).

Strategies for managing preterm labor include the use of the drug indomethacin during surgery, the use of nitric oxide during surgery, and the search for less invasive interventions such as endoscopic surgery. Indomethacin and nitric oxide have been somewhat successful as tocolytic agents, but their application poses the problem of how to drug "mom" without affecting her fetus. Because a fetus is physiologically part of a pregnant woman, it is likely to be affected by anything introduced into her body. Fetal surgeons have attempted to resolve this by collaborating closely with anesthesiologists and fetal physiologists in working out how to use these substances in practice. For example, during surgery tocolytics are administered intravenously and carefully calibrated by anesthesiologists; after surgery, oral tocolysis is used and may be administered and even monitored directly by the pregnant woman. Indomethacin, which was used early on in fetal surgery, is being slowly replaced by nitric oxide but both are still in use (Jennings, MacGillivary et al. 1993; Natuzzi, Ursell et al. 1993). About the newer agent, Dr. Murphy stated enthusiastically, "Nitric oxide makes your smooth muscles relax, and the uterus is a smooth muscle. We have very compelling experimental evidence that the use of nitric oxide--nitric, not nitrous--medications can relax the uterus. Extremely promising."[15]

Despite Dr. Murphy's excitement about nitric oxide, its use in fetal surgery is somewhat controversial. Dr. Siegel, an obstetrician, told me, "The surgical group constantly wants to introduce new things that have not been thoroughly tried. They

---

[15]Nitrous oxide is laughing gas, and would likely cause quite different reactions in the operating room.

have just done that with the nitric oxide stuff. Two out of the last four cases, where they got a child into a nursery, the child bled in its head. The only thing that changed was their pharmacology treatment of the patient." A social worker, Lucy O'Neill, also discussed some complications resulting from earlier forays into the use of nitric oxide: "You know the preterm labor issue is a big deal. We have actually started using this nitric oxide, which is a very unusual thing, and they almost killed somebody because they gave her the wrong suspension. But once we figured it all out, it turns out intraoperatively to be a really good drug for preterm labor." These stories illustrate the ongoing contestation around innovation in fetal surgery, particularly as it relates to maternal management.

The following describes a typical strategy for postoperative management using these tocolytic agents:

> "Once the initial period of uterine contractions has subsided (usually within 5 days), oral tocolytics gradually are substituted for intravenous drugs and then continued throughout the remainder of the pregnancy. Perioperative antibiotics, generally a cephalosporin, are continued for 3 days after the operation. The patient is kept at bedrest for at least 3 days following surgery and then begins a progressive ambulation program...Generally the patient is discharged on only oral tocolytic therapy within 10 days of the procedure" (Harrison and Adzick 1991:288).

The need for daily, ongoing tocolysis, even after patients are discharged, is a source of contention in fetal surgery. Dr. Siegel emphasized that *all* of the patients require tocolysis post-operatively: "They go into labor the minute they come off of tocolytics! The patients stay on pumps giving them tocolytics for the rest of their pregnancies."

Here the women participate in their own medical management as work objects of themselves.

Examining management issues highlights some important professional dynamics in fetal surgery. Conflicts among different specialists, such as discontent regarding the use of tocolytics, are brought sharply into focus. For example, the post-operative period is crucial not only because preterm labor poses a grave threat or because fetal surgeons have not yet developed effective management strategies. It is also a critical period because it is an important site over which fetal surgeons struggle with other practitioners for control. Some of the turf wars described in Chapter 5 are present here, as well, as fetal surgeons attempt to gain control over post-operative maternal management from obstetricians as well as controlling the surgical phase itself. Fetal surgeons' foray into the post-operative period has intensified conflict and friction between fetal surgeons and obstetricians. Further, where the term *management* is used positively to describe strategies for achieving success, the term *mismanagement* is used in this setting in a derogatory way. Both fetal surgeons and obstetricians accuse each other of mismanaging patients with supposedly dire consequences.

Obstetricians, for example, are accused of not understanding maternal physiology and its relationship to patient management. Dr. Nelson remarked, "The obstetricians grossly mismanaged [a patient] in the perioperative period. And in fact almost cost the pregnancy." He went on to say, "that won't happen in the future...We took the time to place mom in an intensive setting, to monitor mom very carefully. I personally stayed at her bedside for 48 hours straight, examining her constantly, doing ultrasound, measurements and recording, and just going over everything." Dr. Murphy told me that "some of the obstetricians and OB nurses are not used to doing big operations and having patients in the ICU. They view the post-operative problem as the preterm labor problem, which is a terrible problem that we're fighting with and

doing research around...But it was clear that patient management went far beyond just management of preterm labor, and we couldn't not be responsible outside of monitoring. That led to friction."

In evaluating a fetal death, Dr. Nelson remarked, "had it not been for some mismanagement of the mom, the fetus probably wouldn't have had any problems...No matter how much data we could give [the obstetricians] telling them they were grossly wrong, they would do what their experience told them was the right thing to do...They don't even want to look at [our data]...Any data we give them they just flat out don't trust, because they've never had that data before and they don't know how to interpret it. In essence, they're out of their league. They've left obstetrics, where they understand what they're doing, and entered the realm of perioperative surgery, physiology they clearly have no handle on. And interestingly enough, are absolutely close-minded and unwilling to learn or to be taught." For their part, obstetricians do not take such criticism lying down and are as adamant as fetal surgeons in accusing the other group of mismanagement. Dr. Siegel told me that "They just shunt patients off...They don't take care of the woman afterward. The perinatal group has now taken over the maternal management." A perinatologist, Dr. Adams, told me that "fetal surgeons tend to lose sight of the forest for the trees. A live fetus is not the only measure of success. My role is to take care of the mother."

One area over which fetal surgery team, sans obstetricians, *have* successfully gained control is non-clinical management strategies, where surveillance strategies are more refined and subtle. For the most part, the fetal team--including surgeons, nurses, social workers, and administrative support personnel--is now fully responsible for managing non-medical aspects of pregnant women's participation in fetal surgery. From the moment they agree to fetal surgery and begin reorganizing their lives to accomodate this major disruption, pregnant women and their partners are closely managed and directed through the fetal surgery process. As Dr. Siegel remarked,

"Tracy [a fetal surgery nurse] is running those patients and their lives." During and immediately following surgery, the women are hospitalized where they can be closely monitored clinically. After surgery, most patients are asked to remain near Hilltop Hospital for the remainder of their pregnancies. For those who cannot afford a hotel, there is a nearby guest house funded by the March of Dimes that can accommodate up to five patient families. It is located near the hospital and provides both lodging and support. Comments at a fetal treatment meeting made by Tracy Knox are fairly typical of how patients are managed: "April is being put up at a guest house until the baby is born. Rather than sending her back to Texas, it made more sense to keep her here so that we can better monitor her and the fetus' condition."

In sum, a variety of clinical management strategies are used in efforts to make fetal surgery more successful. Because pregnant women and their fetuses exist in one body, maternal management is seen as essential to optimizing fetal outcomes. Unlike fetuses, pregnant women are not always defined as patients, yet they are certainly treated as work objects and are managed both clinically and non-clinically in numerous ways. Not all specialists in this domain agree with fetal surgeons' management strategies, leading to fractious turf battles and imputations of mismanagement. Similar tensions are evident in the informed consent process for fetal surgery, discussed next.

"It's a Reality Dump": Informed Consent in Experimental Fetal Surgery

Informed consent is an integral part of human experimentation in the U.S. and other industrialized nations, shaped in part by the ghastly legacy of Nazi medicine and our collective desire to avoid another such inhumane episode. In 1974, the National Research Act initiated mandatory Institutional Review Board committees in hospitals and other facilities conducting clinical research (Perrin 1993). The purpose of IRBs is to oversee all research involving human subjects to ensure that it conforms to ethical

and legal rules. The basic moral principle underlying the doctrine of informed consent is "respect for individual autonomy in the conduct of clinical research" (Thong and Harth 1991:568). This means that patients and clinical subjects have the basic right to decide what happens to their bodies. Prior to any intervention or experimentation, patients must be informed about the treatment, including its trajectory, risks, and benefits, as well as any alternatives. If a treatment is experimental or has not yet been approved, patients must be told. As the Boston Women's Health Book Collective (1994:7) points out, "All information must be given in language that is understandable. And the use of explicit or implicit coercion to steer a patient toward a specific course of action is forbidden."

Despite the clarity with which these principles are often stated in institutional materials, the actual implementation of informed consent in practice may differ considerably. Regulation of informed consent is ambiguous and uneven, with physicians often assuming full and mostly autonomous responsibility for conveying appropriate information. The Boston Women's Health Book Collective (1994:7) points out that "medical speak" tends to distance patients from their physicians, and instructional materials often do not clearly provide the necessary information. Patients may become overwhelmed or intimidated by the terminology or by physicians' attitudes, making them afraid to ask questions (West 1984; Fisher 1988; Todd 1989). Cultural differences also may serve to impede the informed consent process, with patients for whom English is a second language marginalized by a system designed with other interests and consumers in mind. Further, medical practitioners may simply withhold information in order to successfully enroll or maintain human subjects in their protocols.[16] In short, the practice of informed consent often does not conform to moral principles recognizing patient autonomy.

---

[16]The infamous Tuskegee case, in which low-income, illiterate, African-American men with syphilis were misinformed of their diagnoses and denied treatment by the U.S. Public Health Service, is a case in point (Sherwin 1992; Boston Women's Health Book Collective 1994). Jones (1993:275) writes, "Under examination by the press the PHS was not able to locate a formal protocol for the experiment. Later it

This was amply demonstrated in the fetal surgery program at Hilltop Hospital where informed consent is an oft contested but crucial subject. The consent form required by the hospital's IRB and produced by the fetal surgery unit is quite thorough and, on the surface, would seem to provide enough information for pregnant women and their partners to make an informed choice.[17] Its thoroughness may be guided just as much by the principle of non-malfeasance (to do no harm) as by fears of malpractice should experimental fetal surgery go awry. While the form clearly conveys the potentially grave outcomes of carrying a fetus with congenital diaphragmatic hernia (CDH), it also carefully lays out the risks involved in surgery. Consider the following: "Because this treatment is new, its effectiveness is not known...The role of open fetal surgery in treating CDH is unclear. For a fetus like mine where the hole in the diaphragm is large and the diagnosis is made early, the fetus is likely to die and fetal surgery may offer the only hope for survival. My doctors do not know, however, if open fetal surgery is worth the risks involved, or if the results will be any better than with the standard care that is now used after the baby is born...Open fetal surgery is major surgery and has risks associated with it...There is even a slight possibility that I could become infertile or that I might die during this procedure. Even if the surgery is successful the fetus might die."

The consent form also explicitly outlines the procedures to be performed, both during and after surgery. For example: "The surgery is like a cesarean section, with an incision made in my lower abdomen and womb...I will be kept at Hilltop Hospital until I am well enough to leave the hospital...After I am discharged, I will stay in a

---

was learned that one never existed; procedures, it seemed, had simply evolved." He (1993:277) also discusses the men's motivations to participate in such a study: "Since the effects of the disease are so serious, reporters in 1972 wondered why the men agreed to cooperate. The press quickly established that the subjects were mostly poor and illiterate, and that the PHS had offered them incentives to participate. The men received free physical examinations, free rides to and from the clinics, hot meals on examination days, free treatment for minor ailments, and a guarantee that burial stipends would be paid to their survivors."

[17]"Consent to Participate in Open Fetal Surgery Trial for Congenital Diaphragmatic Hernia," May 5, 1992, Hilltop Hospital.

nearby residence to make sure that I am well enough to be out of the hospital...I will remain on medication to prevent premature labor...When I am ready to deliver my baby, I will return to Hilltop Hospital." The form offers an alternative treatment trajectory should a pregnant women not choose fetal surgery, and also explains procedures for ensuring confidentiality. The "costs" section emphasizes that expenses not covered by the patient's insurance company will be paid by a grant from the National Institutes of Health. The form also promises that treatment will be available if the patient or her fetus is injured as a result of participating in fetal surgery, although it does not specify who will pay for such treatment. Attached to the consent form is a copy of Hilltop Hospital's "Experimental Subjects Bill of Rights."

Despite the apparent comprehensiveness of the consent form, there are divergent positions on whether pregnant women who consent to fetal surgery are, in fact, fully and adequately informed. For example, a team of obstetricians at Hilltop Hospital, who also conduct bioethical research, have recently begun a project examining informed consent and decisionmaking in fetal surgery. They plan to interview former patients of the fetal surgery unit retrospectively, using a survey instrument. Their guiding assumption is that "it is easy for the informed consent process to become corrupted. Can patients really know what it's all about?"[18] They also point out that when fetal defects are potentially fatal, as in *all* cases where fetal surgery is an option, women become more vulnerable to arguments that a decision in favor of treatment will "save" their babies. This argument is echoed by Barbara Greenwood, a social worker, who told me that "there are a lot of people who have waited a long time to have a baby, and to discover that they have a lesion like this, they're desperate to do something about it. And they just want to believe so much that it's going to be all right."

---

[18]Personal communication, anonymous informant, April 11, 1995.

Greenwood went on to tell me, in a somewhat anguished voice, that "although [fetal surgeons] were trying to be honest, it was very hard to really paint an accurate picture and expect that anybody would do a thing like this, put themselves through this...We have become increasingly honest and forthright with people because of the consequences of not being that way...But we cannot give informed consent, and no matter how much we tell [the patients] they are still surprised by the discomforts involved, by the risks involved, by the lack of privacy involved, and by the enormous commitment of time involved." In order to prepare patients as much as possible, they are asked to meet with the entire fetal surgery team and tour the hospital. Greenwood takes them to the Neonatal Intensive Care Unit so that they will know what to expect when their babies are born. She remarked, "We get them pretty well revved up and prepared, we take them in, show them around." As Greenwood tells it, this process sounds like a clinical version of the pre-game locker room pep talk.

Yet Greenwood also discussed some situations where the fetal surgery team had not been fully forthcoming. She remarked, "Dr. Graham's worry is always that we nearly pummel people to death with the truth. It's a reality dump, these consent forms. And some people are daunted by that. We had a doctor who came here, a doctor couple, who really knew what we were talking about, I mean talk about informed consent. These were physicians, she was willing to do it and go for it. So we didn't really tell them everything." Greenwood provided sociological insight into why fetal surgeons may not be as forthright as possible: "I think one of the problems is not that Dr. Graham and Dr. Murphy are dishonest by any stretch, but that they are surgeons. And I think that surgeons have to be upbeat or they couldn't get out of bed in the morning. You know, they come here, they cut people open; if they didn't believe in what they did and believe there was a positive outcome at the other end, I think they would become immobilized."

Not everyone in fetal surgery, however, is as sanguine about informed consent as Greenwood portrays the fetal surgeons to be. Dr. Siegel, an obstetrician, believes that pregnant women and their fetuses are being used as "experimental animals" in fetal surgery and bases his objection to congenital diaphragmatic hernia cases on this belief. Initially supportive of CDH experiments, he feels that the high mortality rates for fetuses should prohibit fetal surgeons from continuing with this procedure. He stated, "We don't have to be up in the 40s now or whatever number they're on with as few survivors as there are. We know that there would have been, out of that 40, at least 16 survivors if we did nothing. We don't have 16 survivors after surgery; how can you ethically tell the next woman that she should have surgery?" He also raised some serious questions about whether or not patients are informed of these mortality statistics, and implied that the fetal surgeons are less than fully forthcoming in publishing their findings. He told me, "They don't know about the 40 cases that have been done because how many survivors has not been published. I don't think anywhere but in Tracy's [a nurse] desk you can get survival rates...All that information should be published and available."

Despite this obstetrician's concerns, fetal surgeons seem cognizant of the *need* to provide informed consent, whether or not they manage to achieve this in practice. For example, Dr. Murphy told me that "I think we can give the parents and referring doctors a great deal of information about the natural history of diseases, what the mode of surgery should be, what the timing of surgery should be, whether the timing of the surgery should change depending on clinical circumstances. Giving parents a better idea about the outcomes, that's a tremendous service to be able to do that, to counsel a family...They want to know what the odds are, and they want to know all this information so they can decide whether to terminate the pregnancy or to proceed or under rare circumstances to consider doing something before birth." Dr. Truitt, a sonographer, remarked that "we have learned a tremendous amount about being able

to tell a mother what to expect from a pregnancy. There are tremendous benefits to programs like this one."

"On Behalf of Their Fetuses": Informed Consent By Whom? For Whom?

Issues of how informed consent is enacted in practice are further complicated by the complex technical and physiological requirements of operating on fetuses via pregnant women. In most informed consent situations, patients speak for themselves when they either accept or deny treatment. Both the risks and the benefits are theirs alone. In fetal surgery, however, pregnant women consent to surgery on behalf of their fetuses.[19] Women assume a great deal of risk in fetal surgery and gain no personal clinical benefit, although potentially saving their fetuses' lives is likely considered by them as an emotional and social benefit. Informed consent, like maternal management strategies, embodies the tensions between a maternal/fetal conflict perspective and material aspects of pregnancy. The assumption that women must speak *for their fetuses* illustrates both the view that pregnant women and their fetuses are distinct entities *and* an acknowledgment of their corporeal interrelatedness. With respect to the first point, although fetuses are often assumed to be separate, autonomous entities, they clearly cannot speak for themselves. Somebody must always speak for fetuses, in a culture in which speech and autonomy are valued liberties.[20] Given their social, emotional, and corporeal relationship with fetuses, pregnant women would seem to be the most obvious spokespersons. Yet, the cultural politics of reproduction

---

[19]While pregnancy is unique in the world of human experimentation, some insight can be gleaned from cases where parents consent to procedures on behalf of their children. For example, Thong and Harth (1991:568) found that parents who volunteered their children for clinical trials were less educated, had less social support, and displayed greater health-seeking behavior. They were also more inclined to believe that participating in trials would result in enhanced access to the health care system for their children. Thong and Harth (1991:568) suggest such parents may be more socially disadvantaged and emotionally vulnerable, and that "the informed consent procedure may be acting as a complex psychosocial filter against the cause of social justice."

[20]Haraway (1992:311-12) writes, "Who speaks for the fetus?...[F]or a political semiology of representation, nature and the unborn are even better, epistemologically, than subjugated human adults...Indeed, the effect of this magical operation is to disempower precisely those--in our case, the pregnant woman and the peoples of the forest--who are 'close' to the now-represented 'natural' object."

ensures that women's authority as legitimate representatives of fetuses is highly contested.[21]

Although the political winds buffet fetal surgery in many ways, this domain is remarkable for the degree to which pregnant women are seemingly granted authority to speak for their fetuses. The informed consent process in fetal surgery rests on an assumption that pregnant women must be engaged participants in order for surgery to proceed. In large part, this assumption is based on a recognition of the embodied nature of pregnancy. Dr. Nelson described it this way: "Physiologically the fetus is, for all intents and purposes, a parasite on mom. It can't survive without mom. If it leaves mom, at 24, 25, 26 weeks, then it becomes a parasite on medicine. *Before* 24 weeks it is a parasite...Mom, then, being the dominant organism, can make all the decisions. And her rights clearly outweigh those of the fetus...She's the one who decides everything about it, because she does on a daily basis. It's her decision, it's her kid." This quote conveys both a sense of fetuses as distinct, albeit parasitic, entities *and* respect for pregnant women's authoritative role as arbiters of fetal well-being.

A laboratory technician, Judith Lahey, offered a similar position representing both maternal/conflict ideology and an acknowledgment of women's choices. She stated, "We tend to view the fetus as independent. We're not looking at the mother. We see her as a carrier for the fetus." Lahey went on to say, "There is no ethical conflict clinically because people have freedom of choice. But it should be an informed choice." Lahey believes that the informed consent process in fetal surgery is adequate, and she is not alone. In response to my query about the potential for abuse in fetal surgery, Dr. Hansen told me, "At least at present, women choose to come to

---

[21]Third-parties increasingly seek authority to speak on behalf of fetal rights and interests (Johnsen 1987; Jost 1989; Macklin 1990; Nelson and Milliken 1990; Ryan 1990; Steinbock 1992). As Fletcher and Jonsen (1991:15) point out, consent for fetal treatments may be obtained from either the pregnant woman or from "an impartial physician, involved in the fetal medicine team, to 'speak for' the fetus." Of course, there is no such thing as an impartial physician.

us for our help...We feel that the parents have control over what to do." Both of these quotes illustrate some of the tensions at play in fetal surgery between an emphasis on maternal/fetal conflict and a discourse of women's choice and autonomy.

Given the prevalence of a rhetoric of choice in fetal surgery, it would be easy to assume that pregnant women's authority to speak for their fetuses is universally recognized in this domain. Yet in the above quotes, women's autonomy and choice is recognized principally when informed consent is at issue. These informants, for the most part, are talking about women's "choice" to participate in experimental fetal surgery. Because fetal surgery is experimental, it cannot proceed without pregnant women's ostensibly informed and engaged participation. In one sense, then, fetal surgeons have no choice *but* to recognize women's authority to either allow or prevent fetal surgery. Recognizing women's legitimacy to accept treatment on behalf of their fetuses makes fetal surgery possible. In other words, women's consent, whether truly informed or not, enables fetal surgery as an experimental treatment, and medical workers certainly realize this.

Yet, despite this limited recognition of pregnant women's autonomy in the informed consent process, they are not always seen as legitimate spokespersons in fetal surgery once the trajectory has been triggered by their initial consent. The maternal/fetal conflict ideology is pervasive in this domain, and medical workers often seek to position themselves as experts on fetuses. Social worker Barbara Greenwood, for example, told me about a patient who had gone home against her surgeon's orders. Greenwood expressed dismay about this woman's "incorrect" decision while also reaffirming the team's stance on patient autonomy: "What we need to say to families is look, you know if you can't stay here then we can't do the surgeries, because we don't trust that any other hospital can take care of you as well as we can." Thus, respect for patient autonomy as outlined in institutional guidelines on human experimentation may be mutated in practice by a variety of factors.

In short, authority is contingent upon how the informed consent process occurs in the medical setting. Women's signatures are necessary on informed consent documents, but the dynamics of the medical setting may shape their subsequent participation in more subtle ways. This suggests that women's autonomy to make decisions about their reproductive health is both contextual and contingent. Pregnant women's authority to act on behalf of their fetuses is contingent upon the particular needs and interests of fetal surgeons and the demands of fetal treatment. In the fetal surgery setting, women's authority is more likely to be recognized when it is most needed by medical workers. Next I discuss the related issues of conflict between "lay" and "professional" perspectives in this domain, focusing on situations in which women's authority and autonomy are contested.

Who Decides? Lay vs. Professional Control in Clinical Decisionmaking

Chapter 5 detailed an array of conflicts among different practitioners in fetal surgery, largely centered around multiple definitions of the fetal work object. Not only is fetal surgery a site of contestation among professionals, it also a site for differences between professionals and laypersons. Pregnant women and their families bring their own unique knowledges and interpretations to the fetal surgery experience, and these may differ considerably from the professional, "expert" perspectives claimed by fetal surgeons and other medical workers in the situation. Along a number of dimensions, ranging from evaluations of success and failure to selecting a treatment option, pregnant women's decisions and expertise are often challenged in fetal surgery. Once initial consent for fetal surgery is obtained, respect for women's authority as spokespersons for their fetuses seems to diminish considerably. This is not to suggest that the fetal surgery team is insidiously "out to get" pregnant women. Nor does it mean that the women passively accede to physicians' requests like the sheep which preceded them in the fetal surgery enterprise. The reality, as is often the case,

is more complicated, contingent, and subtle, reflecting the many factors which come together to shape pregnant women's experiences in a specific clinical setting.

One important dimension of conflict concerns how fetal surgery is defined and evaluated by its participants. In identifying a particular operation as successful or not, fetal surgeons and patients use different criteria. Most pregnant women choose fetal surgery with the hope that they will have a healthy baby at the end, a goal certainly shared by fetal surgeons. Patients are, according to Lucy O'Neill, "people who have waited a long time to have a baby" and who "are very committed." Their downstream goals are to "save" their fetuses however possible, and their reaction to a failure may be very different from the fetal surgeons'. Susan Johnson, whose surgery was successful, described the operation as an unqualified success and her daughter as "a miracle baby." For Susan, the success of the surgery extended beyond the operation and into the fabric of her family's lives. Four years after surgery, Elizabeth Ann is still considered a miracle baby. Wendy, another patient, qualified success in a slightly different way: "It was worth the effort. Even if it had not been successful, we would have known that we'd at least tried and he might have had a slim chance. I feel sure that if we had not done anything, he wouldn't have survived the pregnancy."

Yet fetal surgeons are far more interested in the *immediate* clinical success of fetal operations, often not seeming to think beyond the walls of the operating room. Dr. Graham's comment that "we don't pull out live babies" leaves little room for downstream implications of surgery, such as a stint in the NICU or how the family will cope with a possibly very sick or permanently impaired baby. In a similar vein, Dr. Hansen told me that "the nature of fetal surgery is that once you opt to run the race, the goal is to win." When asked how he defined success and failure in fetal surgery, Dr. Hansen remarked, "Surgeries are kind of a unique therapy. You do a specific invasive intervention with lots of different risks and hope to obtain a specific goal, usually cure or palliation. Ideally, you'd like to get somebody to a point of comfortable,

functional living." He defined a failed surgery as, "depending on what the goal is, either cure or palliation. Obviously, if you aren't able to cure somebody then that would be some degree of failure if that was your intention. But even if you can't cure somebody, in the process you can palliate their pain or disability...A miserable failure would be to make them worse off than they were before you operated and an even more miserable failure would be to make them worse off than the natural history of the disease would make them. And that should be foreseeable pre-operatively most of the time."

Dr. Nelson offered a similar view when asked the same question. He responded, "If you're going to go 80% of the way, you've got to finish the race. You've got to go the whole way. Because if you fail not having gone the whole way, did you really fail? Did you fail for the stupidity of not going the whole way or did you fail because it was truly the wrong thing to do? You haven't answered the question if you don't do it right. So we have to do it right...And we're the only people in the world who can do this. We're the only people in the world who can *ask* the questions and we're the only people in the world who can *answer* the question. We have to do it right. We're under the world's spotlight." For Hansen and Nelson, then, success and failure are intimately tied to the survival of fetal surgery as an experimental protocol, as a practice geared toward demonstrating the viability of operating on unborn babies, and as reflective of the institutional standing of Hilltop Hospital.

Ironically, it is precisely these evaluative criteria which are contested by obstetricians and others, as discussed in Chapter 5. Dr. Siegel told me, "The reason that [maternal] complications are unacceptable is you have to look at what the benefit is. The same cost would be acceptable if the benefit is fine...We've learned a lot. But that doesn't mean a fetus should have a marsupialization of the bladder today or a CDH." Here, Siegel points to high fetal mortality rates as indicative of fetal surgery's limited success, while simultaneously recognizing that important clinical and scientific

"discoveries" have been made through pursuing fetal surgery. Dr. Truitt, a sonographer, shares these views and remarked, "The bad news is that we've had failure. The good news is that we're a long way from being out of ideas." For both these clinicians, success and failure are linked to issues beyond just saving babies. They are at least cognizant of the degree of maternal risk associated with fetal surgery as well as the long-term viability of the specialty.

For fetal surgeons, in contrast, success most often refers to broader issues germane to the enterprise of fetal surgery and not just individual clinical cases, although these too are important. Fetal surgeons have other criteria for success which reflect their positions as clinical researchers. Recall the discussion in Chapter 5 about the scientific payoffs of experimental fetal surgery. If something useful can be learned from a specific case, even if the fetus dies, the surgeons may consider the case a success of sorts. Surgeons are also concerned about the future success of fetal surgery. Dr. Nelson told me, "We finally know what the hell we're doing in some small way. And we will succeed. It's very obvious to me now. It was not a year ago. I was very frustrated...I thought, we're working on all these kids. Why? What are we learning? What are we doing? We're just murdering babies. It's just a fancy, expensive way to kill kids. But now that we're taking measurements, we're doing the right thing. We're understanding, and we'll succeed. There's no doubt that we'll succeed." Certainly pregnant women desperate to save their babies do not give as much thought to the future enterprise of fetal surgery as the fetal surgeons do.

Another way in which differences between medical workers and pregnant women are manifest is in constructions of pregnant women as "problem" patients. To some degree, this reflects attempts to control the circumstances of fetal surgery, as with the maternal management strategies described above. The staff have a strong sense that they invest a great deal in pregnant women, and they become very disappointed when the women do not behave in expected or hoped for ways. Barbara

Greenwood, a social worker, remarked, "We feel incredibly indebted to the patients for taking a risk like this, as long as they're cooperating. As soon as they tell us they have to get home, we're not so sure we like them anymore." Where pregnant women cannot be managed by Hilltop medical staff, they are defined as non-compliant. Greenwood went on to tell me, "These are difficult patients to manage medically. They become difficult compliance problems, and they do a lot of acting out around these lines...You really need people who understand the consequences of this, and who are responsible in their lives." Women are expected to invest as much of themselves in the fetal work object as possible and to work as hard as the fetal surgery team works at saving babies. This has implications not only for pregnant women's experiences in fetal surgery, but also for how medical workers conceptualize and treat the women in their practices.

In discussing maternal complications resulting from unsuccessful surgery, Harrison (1991:289) wrote, "[P]oor patient compliance occurred in one case--the mother stopped her oral tocolytics and promptly went into labor and delivered vaginally." Although the fetus did not die in this case, this patient subverted standard operating procedure in which cesarean section deliveries are expected of *all* women following fetal surgery. This is an important issue, as surgeons are reliant in the post-operative period on pregnant women following their orders. An educational video sent to patients before surgery illustrates how the fetal surgery team attempts to teach compliance *before* the operation ever takes place. The narrator states, "Before you leave the hospital, we will teach you how to monitor your contractions and deliver medication to control preterm labor. Remember, you'll have to be on almost continuous bedrest during the rest of your pregnancy."

Yet such expectations of compliance, like other maternal management strategies, may be unreasonable in light of just how difficult the post-operative period is for pregnant women. One patient remarked, "Once I started coming off of morphine

and they increased the two drugs, magnesium sulfate and terbutaline, that really punched me out. That really knocked me out. I mean, it was the worst time, the third or fourth day after surgery." Liz Amos, an obstetrician who works with patients in the post-operative period, stated, "They wake up out of general anesthesia like a truck has run over them," and a nurse described the women as "wet dishrags." Obviously, expecting full compliance in the post-operative period and being disappointed when it is not forthcoming seems remarkably unfair given what these patients have just gone through. It would seem that it is during this acknowledged "most difficult period" that the patients especially need the Hilltop medical staff to "still like them."

Differences also occur around treatment decisions and what should be appropriate criteria for pursuing different therapeutic trajectories. Physicians are often reluctant to trust that pregnant women possess adequate knowledge of their own cases and bodies to make a sound decision or to fully understand the decisions that the physicians make on their behalf. For example, as a result of several fetal deaths which occurred during surgery, many of the medical staff felt that neonatal equipment should be made available to provide care for later gestation fetuses which could not be put back into the womb and still survive. Yet the fetal surgeons expressed reluctance at introducing neonatal care into the surgical environment, in part because that meant also introducing another set of clinical decisionmakers--the neonatologists--who might assume control over the neonatal patient if it is permanently removed from the uterus and survives. It was this discussion about neonatal technology which prompted Dr. Graham's comment from above, that fetal surgeons either put fetuses back in alive or take them out dead, leaving little room for neonatologists to encroach on their territory. In arguing with other staff about the feasibility of making neonatal resuscitation equipment available in the operating room, Dr. Graham stated that he could foresee two problems: "explaining it to the mother" and "having it there logistically." Ironically, despite differences among the clinical staff, it was clear that

most of the clinical staff believed that women were incapable of recognizing the significance of this technology. This conversation may well reflect medical workers' distrust of women's capacity to understand technology, but it may also signify practitioners' unwillingness to expose their turf wars pregnant women.

Pregnant women and medical staff conflict over appropriate treatment trajectories, as well, reflecting an experiential split between lay and professional boundaries. As discussed in Chapter 5, fetal surgeons, obstetricians, and other specialists tend to approach problems from a clinical perspective, often opting for more rather than less intervention. Pregnant women, on the other hand, tend to approach problems within the broader framework of their health and lives. One case in particular, presented by Dr. Siegel during a staff meeting, illustrates this sometimes tense dynamic.

Kelly, a young woman carrying twin fetuses at about twenty weeks gestation, was referred to Hilltop Hospital because one of her fetuses was "stuck" (i.e., not growing) and the other, healthier fetus was already twice as large. She had been counseled by her regular physician to abort the smaller fetus, but she wanted a second opinion. Dr. Siegel told her that she had four options: terminate the entire pregnancy; abort the smaller fetus; undergo fetal surgery to remove the smaller twin; or undergo fetal surgery to tie off the cord to the smaller fetus, thus allowing it to die in utero. All options presented significant problems and risk, including the questionable survival of the remaining fetus. Kelly and her partner told Dr. Siegel that an open surgical procedure was "not acceptable" and that they were "not willing to risk the birth of an abnormal fetus." In relaying this case to his colleagues, Dr. Siegel outlined a number of problems associated with it, including the fact that this couple had "put boundaries on what they're willing to do." Other medical staff at the meeting grumbled about this, with one person describing Kelly's "irrational boundaries" as unreasonable. Dr. Siegel's preferred treatment plan was to "wait a few weeks and do nothing to see if

nature resolves the problem; [Kelly and her partner] would feel better and we'd feel better."

This case was discussed again a month later at the next fetal treatment meeting. After leaving Hilltop Hospital, Kelly had decided to pursue selective termination of the stuck fetus at another hospital. She underwent "aggressive amniocentesis" which, according to one of the obstetricians at Hilltop, "apparently didn't work very well." Kelly again presented at Hilltop Hospital, with an even sicker stuck fetus. Dr. Siegel said that Kelly and her partner saw the situation as "totally unacceptable," and did not want either twin if the smaller one would have a problem. Dr. Siegel, who initially wanted to hold off on treating or removing the smaller fetus, now agreed to operate on the smaller fetus. He used a technique in which a coil is wrapped tightly around the umbilical cord, thereby shutting off the blood and oxygen supply from the placenta. The goal is to kill the stuck fetus before the healthier fetus is affected by the procedure. Yet the procedure was only partially successful; within 24 hours, flow was reestablished to the larger fetus and within 48 hours to the smaller fetus. Kelly and her partner "were adamant that they did not want to deliver an abnormal fetus." Yet a few days later, the smaller fetus had died and the remaining fetus was growing at 24 weeks. However, Dr. Siegel was disturbed because the surviving fetus may have already been damaged by its stuck twin. He remarked, "Now it's a wait and see game, but Kelly has achieved what she wanted. The smaller fetus is dead." His tone indicated that he clearly disagreed with Kelly's treatment decisions, despite his agreement to go ahead with it.

Although Dr. Siegel ultimately went along with Kelly's decision, this is not always the case in fetal surgery. In addition to not fully trusting pregnant women's competence to make decisions about their own care and treatment, members of the fetal surgery team sometimes engage in subtle coercion to "encourage" them to accept a particular trajectory. As Barbara Greenwood remarked, "We delay them, we

convince them, we get angry at them, but in the end it's their lives. If their decision to come out here is that we may need them to stay here, then the onus is on us. We say to them, you've got to come here, you've got to stay here, figure out how you can arrange your life. If you want this, we need you here." Given these "persuasive" conditions, it is not surprising that women's own experiences and knowledge often do not fully prepare them for the rigors of fetal surgery. One patient, Debbie, described her experience: "I just remember everybody telling me that it was really horrendous. That the drugs and the aftercare were bad, but it just didn't register that I was going to be going through as much as I went through." It is these fundamentally different definitions of the situation (Thomas and Thomas 1970; Thomas 1978) that shape conflict between medical workers and pregnant women in fetal surgery.

Another way in which women's experiences differ is in how much clinical knowledge and/or experience they have. A few women who came to Hilltop Hospital for fetal surgery have clinical backgrounds; one, for example, is a physician. Yet the majority of fetal surgery patients have no clinical training; for them, the world of fetal surgery is complex, foreign, and confusing. Susan Johnson described this experience for me, relaying her story as if she were a traveler in a foreign land where nobody spoke English and the signs were incomprehensible. She told me that not only was fetal surgery "a hard thing to do physically," but that she often felt like the medical personnel "talked down" to her. Although she found the fetal surgeons supportive, their arcane language created barriers between doctor and patient. Susan and her husband, Jim, developed a close, friendly relationship with Dr. Murphy, but found other surgeons less accessible "because they were so busy." For example, she spoke of Dr. Graham with a sort of respectful awe, a noticeable contrast to the affectionate tone she used when talking about Dr. Murphy.

Because she felt uncomfortable not sharing the knowledge that surgeons and other medical staff brought to their work, Susan decided to do something about it. She

clearly wanted to seize some measure of autonomy and control for herself, and so became an audodidact, reading as much as she could find about fetal surgery.[22] I found Susan to be at least as knowledgeable as most of the clinical staff, perhaps more so than some of them. She was well-versed in the history of fetal surgery experimentation; maternal and fetal morbidity and mortality statistics; maternal risks and complications; different types of operations; and published outcomes. She stated proudly, "I know more about fetal surgery than most of the nurses and social workers." This was a telling statement, as Susan had complained to me that she had several uncomfortable encounters with nurses and social workers. She found one social worker in particular to be very unsupportive and judgmental.

Susan's experiences illustrate that not only do pregnant women and their physicians sometimes clash, but other medical workers may also be sources of conflict. In contrast to the women's own experiential frameworks, clinical staff may appear to be "talking down" as they articulate their own professional perspectives. Even social workers, who consider themselves advocates for the moms, are sometimes seen as being positioned on the other side of the lay/professional boundary. This should not be surprising, given Barbara Greenwood's blunt comments about what is expected of the pregnant women both clinically and emotionally. If medical staff behave as if pregnant women will be non-compliant, "problem patients" who must be carefully managed, then women's resistance strikes one as a logical response. Within the institutional setting of fetal surgery, women's work in obtaining knowledge and choosing particular treatments exists side by side with fetal surgeons' work in attempting to save babies. All these different sets of practices coalesce to shape pregnant women's experiences in this domain as both working subjects and work objects.

---

[22]Epstein (1995) writes about autodidacts in the HIV/AIDS arena, focusing on how the acquisition of knowledge can be a powerful tool in dealing with clinicians and biomedical institutions.

Conclusions

I began this chapter with a discussion of the maternal/fetal conflict paradigm, in which pregnant women and their fetuses are seen as distinct entities. I suggested that a focus on maternal practices, or the engaged work that women do on behalf of their fetuses/children, provides one avenue for challenging this perspective. This chapter has presented some of the tensions which exist in experimental fetal surgery between practices which reinforce the maternal/fetal conflict paradigm and those which challenge it. By emphasizing women's active participation in fetal surgery, assumptions that they are merely passive technologies in support of the fetal patient are rendered invalid. This is not to imply that women are not also constructed as technomoms (defined in Chapter 2) through various practices in fetal surgery. Rather, it is to argue that pregnant women in fetal surgery are *simultaneously* engaged and implicated actors; working subjects and work objects; part of meaningful maternal/fetal relationships and enmeshed in discourses of maternal/fetal conflict. These tensions, woven into the very fabric of fetal surgery, have much to do with the material aspects of a practice in which pregnant women are the vehicles through which surgeons must access the fetal patient.

Within medicine and popular culture, as we have seen in previous chapters, fetal surgery is conceptualized as a pediatric issue. Fetuses have been made into fetal patients, and most work in this emergent specialty is organized around fetal health problems and biomedical needs. Many fetal surgeons, for example, have been trained as pediatric surgeons rather than as obstetricians, illustrating that fetal surgery is seen as pediatric surgery but "with a difference." Framing fetal surgery as a pediatric issue renders pregnant women barriers to be breached, bodies to be manipulated, and constraints to be managed if they are made visible at all. However, reframing fetal surgery as a women's health issue challenges this approach and allows

us to critically analyze women's complicated participation in this domain, as I have done here. A basic assumption of a women's health approach is that "women's experience in the health care system is not an isolated phenomenon, but one which is influenced by and in turn influences wider societal themes" (Olesen and Lewin 1985:3). Thus, a major theme in this chapter has been attention to pregnant women's varied experiences in fetal surgery, including specific health issues and the wider contexts in which they exist.

Toward this end, I have attempted in this chapter to highlight some of the ways in which women's broader lives are shaped by fetal surgery. Their choices to undergo fetal surgery are influenced by previous experiences as well as by political beliefs, most notably their positions on abortion. A women's health framework enables a critical understanding of how such reproductive politics imbue and mold fetal surgery, and how fetal surgery fits into the extant structure of women's emotional and political lives. Not only do abortion politics resonate within fetal surgery, but they are amplified by fetal surgery's locatedness as a politicized reproductive practice.[23] Although ostensibly focused only on fetuses, fetal surgery is firmly situated within the wider field of maternal-fetal medicine in which women's reproductive health is a core element. Thus, not only does a women's health framework challenge fetal surgery's identification as a pediatric issue, but it also redefines it as a practice of great consequence for women's reproductive and potentially post-reproductive experiences in the health care system.

Further, in linking pregnant women's experiences to their broader social worlds, this chapter also focused on the organizational work women do in attempting to cope with the "unimagined horror" of a defective fetus, as Barbara Greenwood phrased it. Pregnant women who choose fetal surgery must often profoundly

---

[23]Joffe (1995:179) quotes an abortion provider: "It comes down to who is the patient. Is the woman the patient, or is the fetus the patient? One or the other is the patient. I've never heard a fetus talk to me. I've heard thousands and thousands of women share their pain, their desperation, their helplessness...especially with the younger patients."

reorganize their lives, often traveling great distances, spending considerable sums of money, and leaving other family members behind. Contrary to the pervasive maternal/fetal conflict paradigm, in which women's interests are thought to be quite different from their fetuses', women's actual work illustrates just how committed these women are to the concept of the fetal patient. Examining women's engaged participation in the making of *their* unborn patient goes far in debunking the maternal/fetal conflict paradigm in favor of an approach which recognizes maternal/fetal relationships as both social and embodied while their specificities remain empirical questions situated in lived experiences. The women described here who chose fetal surgery clearly have their fetuses' interests at heart and are willing to do as much as possible to save their babies. They may be both heroes and technomoms, but they are also agents of their own medicalization (Leavitt 1986; Bell 1987), explicitly refuting the conflict paradigm.

Yet, while recognizing women's engaged complicity in the emergence of fetal surgery, a women's health perspective also forces us to address how this practice impacts women's morbidity and mortality. Although surgeons are proud of the fact that they "haven't lost a mom yet," as we have seen women's health may be severely compromised in fetal surgery. Almost all aspects of fetal surgery, from prenatal diagnosis to post-operative care, impact women's health. As participants in fetal surgery, pregnant women engage in body work of various types, from surgical manipulations performed on them to subsequent self-management of tocolytic agents to prevent preterm labor. As the patients quoted above illustrate, the intensive regimen of surgery, post-operative management, and delivery by cesarean section takes a considerable toll on pregnant women's bodies, and the sequelae remain to be studied. A women's health framework brings into sharp focus the implications for women of risk and safety issues, maternal management strategies, the informed consent process, and distinctions between lay and professional boundaries in clinical

decisionmaking. Thus, an important component of reframing fetal surgery as a women's health issue is recognizing that making fetuses into unborn patients has significant implications for women's health, bodies, and lives.

Chapter 7

BEYOND THE OPERATING ROOM: CONCLUSIONS AND IMPLICATIONS

"What we experience in various and specific milieux...is often caused by structural changes...To be aware of the idea of social structure and to use it with sensibility is to be capable of tracing such linkages among a great variety of milieux. To be able to do that is to possess the sociological imagination."
(Mills 1959:10-11)

A decade ago, Margaret Atwood (1985) published her chilling tale of one woman's reproductive nightmare in a fictional theocracy called the Republic of Gilead. It is a place where women are reduced to their so-called "natural," "biological" roles, namely reproduction. They can no longer read, own property, spend money, care for their own children, or choose their own mates. The fertile women, called handmaids, are recipients of the master's sperm and surrogates for his barren wife; insemination is a collective ceremony devoid of warmth and love. In this new world order shaped by conservative religious forces, pregnancy and birth are exalted and celebrated as essential processes, but the products of reproductive labor belong to the fathers. *The Handmaid's Tale* shares with other feminist studies of reproduction an insightful analysis of how women may be reconfigured by shifting political, religious, and national borders.

In 1988, upon the publication of her next novel, *Cat's Eye*, Atwood spoke to a standing-room only crowd at the University of Chicago. During the question and answer section which followed Atwood's presentation, *The Handmaid's Tale* garnered the lion's share of attention. Most questions seemed to revolve around two themes: could a place such as Gilead exist in "real" life, and how did Atwood ever conceive of such a horrific plot. The author replied that she had a large filing cabinet in her office

filled with newspaper clippings and magazine articles detailing the rise of the Religious Right and increasing attacks on women's reproductive freedom in the U.S. As she phrased it, her story originated in "the news of the day;" the seeds of a future Gilead are being sown now. Atwood's skill as a storyteller was in linking these different yet related social phenomena in a compelling narrative. She collected the cultural flotsam and jetsam of everyday life and made visible and visceral some of its deeper meanings, connections, and implications.

I have attempted to do something similar in this dissertation, although with careful attention to methodological concerns regarding representations of the "real" world. As an interpretive enterprise, sociology concerns itself with making visible the often hidden connections among phenomena. It provides us with tools for investigating the collective nature of the rich and varied practices which constitute the fabric of social life. My story of one such practice, experimental fetal surgery, brings together and makes sense of a disparate array of elements: medical work, cultural politics, medical practitioners' goals and interests, pregnant women's experiences, technologies, scientific knowledge, institutional hierarchies, fetal work objects, and so on. This story spans three decades and two oceans, linking historical work in the 1960s in New Zealand and Puerto Rico to contemporary work in the U.S. Its plot is deceptively simple: how medical work and the politics of reproduction have simultaneously shaped the making of the unborn patient in the twentieth century, and, in the process, transformed fetuses, pregnant women, and the field of reproductive medicine. In this conclusion, I summarize my major arguments, highlight theoretical contributions, and discuss some important implications of this research for women's health policy.

Summary of Key Arguments

My story of experimental fetal surgery began in Chapter 1 with a description of the current institutional contours of the specialty. As we saw, fetal surgery is practiced at only a handful of medical centers in the world, with most of the experimental work centered at Hilltop Hospital in the U.S. Pregnant women whose fetuses are diagnosed with terminal conditions are referred to Hilltop for subsequent diagnosis and possible treatment. I argued that fetal surgery raises a number of significant questions with respect to medical, cultural, and economic investments in (some) fetuses. In a contested social and political context where constructions of fetal ontology matter, these investments in fetuses have major implications for women's health and lives.

Chapter 2 introduced the concept of *work objects*, or the material objects (human, non-human, technical, or hybrid) around which actors construct meanings and organize their work practices. I defined fetuses and pregnant women as work objects in experimental fetal surgery, and explored some possible consequences of these constructions. In illustrating how this concept might be useful in studies of medicine and science, I comparatively analyzed experimental fetal surgery and fetal tissue research. Focus was both on the contested political history of fetal tissue research in which these practices are situated, as well on how fetal and maternal work objects are configured in each. I argued that global and local conceptions of fetuses and pregnant women exist alongside each other. The work objects themselves link different domains such as culture, politics, technoscience, and biomedicine, and thus constitute the traffic between these interrelated worlds.

From a discussion of work objects, I moved on to an historical analysis of fetal surgery in Chapter 3, beginning with experimental efforts in the 1960s. Following the work itself required to transform fetuses into patients, I charted the historical constellation of different actors, events, and technologies in this domain. More

specifically, I explored the work of William Liley, Graham Liggins, and their many colleagues at National Women's Hospital in Auckland, New Zealand. Liggins' development of non-surgical fetal treatments and Liley's innovation of a key surgical technique firmly situate New Zealand as a birthplace of fetal medicine. In narrating this story, I focused on the collective medical and scientific work undergirding the emergence of these techniques and their role in crafting fetal patienthood. I also examined links between Liley's political activism and his professional life, drawing connections between his anti-abortion views and his advocacy on behalf of the fetal patient. Leaving New Zealand and moving on to New York and Puerto Rico, I discussed the emergence of open fetal surgery in animals and humans through the work of Vincent Freda, Karliss Adamsons, and their colleagues. I explored both the experimental underpinnings of these innovations as well as their relationship to reproductive politics.

Chapter 4 provided a bridge of sorts between the historical work of the 1960s and renewed interest in open fetal surgery in the early 1980s. There I argued that clinical research is a useful site for studying the imbrications of medicine, science, and technology in practice. As a hybrid clinical practice, fetal surgery is shaped by linkages among a range of different practices, each of which facilitates access to the fetal work object. For example, fetal physiology has been integrated into contemporary fetal surgical practices in attempts to improve outcomes. The introduction of ultrasound and other diagnostic technologies spurred the emergence of fetal surgery in the 1980s and may, in part, explain the lag between these efforts and the earlier work of the 1960s. The use of research animals, primarily sheep and monkeys, has offered both scientific knowledge and legitimation to fetal surgery, while the fetal wound healing paradigm alters understandings of how the basic research/clinical practice distinction unfolds in practice. In sum, all of these different activities contributed to the making of the unborn patient and the emergence of fetal

surgery as a hybrid clinical practice. Examining the work of each illustrates how the borders between what we think of as medicine, science, and technology are porous, overlapping, and shifting.

In Chapter 5, I focused on differences in fetal surgery from another angle, drawing on ethnographic research in the Fetal Treatment Unit at Hilltop Hospital. Framing fetal surgery as a collective enterprise, I examined the diverse skills, talents, and experiences required to pull off a procedure as complicated as operating on an unborn fetus. There is a clear division of labor in fetal surgery which is constantly reinforced through professional interaction. I argued that this very diversity and all of the interactions it produces shapes what fetal surgery looks like in practice. More specifically, cooperation among practitioners makes fetal surgery possible, while conflict based on differences threatens its viability at every turn. Focusing in particular on different definitions of work objects, different criteria for patient selection, and different views of a disease and its treatment, I defined fetal surgery as a processual order created and maintained through continuous negotiation among its heterogeneous participants.

Chapter 6 addressed the experiences of pregnant women in fetal surgery, focusing on a range of maternal practices which challenge the maternal/fetal conflict paradigm. I defined pregnant women as *engaged* participants, willing to do what it takes on behalf of *their* fetal patients which are quite meaningful. I examined women's choices and politics in fetal surgery, the organizational and body work they do, and women's assumptions of health risks as examples of their engagement. I also addressed tensions in fetal surgery stemming from the materiality of fetal surgery, in which the fetal patient is located inside women's bodies. These included maternal management strategies, the informed consent process, and the significance of lay versus professional control in clinical decisionmaking. I showed that pregnant women in fetal surgery are both working subjects and work objects; engaged and implicated

actors; part of social maternal/fetal relationships and enmeshed in discourses of maternal/fetal conflict. Drawing on these tensions, I reframed fetal surgery as a women's health issue, pointing to some clinical implications of this practice for women while also showing how women may be agents of their own medicalization.

In sum, this story has been about how a new medical specialty, fetal surgery, and a new social and clinical category, the unborn patient, have emerged simultaneously through the collective work of participants in this domain. This process has been shaped historically by reproductive politics and controversy surrounding human fetal work objects, as well as by cultural conceptions of pregnancy. Next, I focus more specifically on some theoretical contributions of this research.

Theoretical Significance of Work Objects

This study is of significance both to medical sociology and to social and cultural studies of science and technology. Theoretically, this research serves to cross-fertilize these two areas of inquiry. By empirically following the medical work involved in transforming fetuses into patients, I have offered an understanding of how medicine, science, and technology intersect in a particular domain. From the perspective of medical sociology, attention to collective medical work and the social construction of a new category of patient is consistent with disciplinary interests. The innovative feature of my analysis is in expanding the medical sociological gaze to encompass the *contents* of medical work, including its scientific and technical core. In addition, attention to the specifics of practice is consistent with approaches in social and cultural studies of science and technology. My analysis broadens this framework to include medicine and its objects as topics worthy of investigation.

Moreover, the concept of *work object* itself cuts across both areas of inquiry, serving as a useful tool with which to analyze the making of the unborn patient through and across different types of medical and scientific practices. The significance

of this concept is in examining how the "nature" of the object, or its material and symbolic characteristics and properties, shapes work practices, while the object itself is simultaneously and mutually shaped by the work and its social contexts. Interpretive emphasis remains focused on human action and meaning, yet incorporates an understanding of how material work objects may constrain, enable, or otherwise influence these processes. In fetal surgery, this is essential for understanding how the physical dimensions of pregnancy in which fetuses are located inside women's bodies impedes access to fetal work objects. The concept also provides a means of analyzing how different spheres of social life, such as medical work and reproductive politics, are linked through specific practices at local sites.

Yet work objects are useful analytical tools in areas of inquiry beyond medical sociology and social and cultural studies of science and technology. This concept is theoretically significant for the broader enterprise of sociological studies of work. For example, whereas in medical sociology analysis centers on human patients as work objects, one might focus on animal models as work objects in scientific research, as I have done in this dissertation. In research on agricultural work, objects might include soil, crops, predatory insects, or farm animals. In research on automation, objects might include computers, assembly-line machinery, or robotics. In research on industrial work, objects might include forklifts, steel, or machine presses. In research on sex workers, objects might include clients, sex toys, or safer sex technologies (Moore 1996). In other words, work objects are those material and symbolic entities around which actors organize their work practices. They are both meaningful and physically obdurate.

A number of analytical questions may be generated about work objects. How are work practices organized around specific objects? What meanings are ascribed to work objects? Are multiple work objects prioritized in a work situation? Are work objects contested? Who claims work objects and makes decisions about them? How

do both work objects and work practices change as objects move through and across different domains? How do work objects constrain certain types of practices? How do work objects relate to other concepts, such as tools, in understandings of work? All of these questions reflect abiding sociological interest in collective aspects of work and its social organization. Their specific nature represents the sociological enterprise of using a broadly defined concept to generate questions and answers about local, empirical sites and practices.

Implications for Women's Health Policy

It is clear from my story that a number of different actors care about fetal surgery: patients and their families, surgeons, obstetricians, perinatologists sonographers, nurses, social workers, fetal physiologists, abortion activists, and many others. Although their reasons may be different, all of these actors *care*, in a pragmatic sense, about fetal patients and pregnant women. They care so much, in fact, that they have organized a large part of their working lives around fetal and maternal work objects, which have been defined as meaningful in these social worlds. These actors have made clinical, scientific, technical, cultural, economic, and even emotional investments in fetuses and pregnant women. Their allegiances to different patients in fetal surgery may diverge along specialty lines, or perhaps other cleavages, but through their work practices all these actors have contributed to the social debut of the unborn patient and the emergence of experimental fetal surgery as a new specialty.

Who else cares about fetal surgery? Or, rather, who *should* care about fetal surgery? Most significantly, people who care about women's health should care about fetal surgery for a range of different reasons. Currently only a small number of pregnant women whose fetuses are diagnosed with an abnormality are presented with fetal surgery as an option for treatment. Because it is experimental and risky for both

fetuses and moms, fetal surgery is limited to lethal conditions where the fetus would likely die if left untreated. However, there is no clinical benefit to pregnant women in choosing fetal surgery, making other, less risky treatments more attractive. As we have seen here, women's motivations for selecting fetal surgery are related to the broader context of their lives. Reproductive politics, social support, and engagement with their fetuses are all factors in women's decisionmaking processes. Yet from prenatal diagnosis to clinicians' presentation of treatment decisions, subtle factors shape women's choices toward some trajectories and not others. Women who choose fetal surgery are portrayed as "heroes," while those who challenge physicians are represented as selfish or non-compliant.

Critically examining women's "choices" in this domain is important, as fetal surgery has significant implications for women's health. What if fetal surgery eventually becomes a routine procedure for many different anatomical defects? How will a woman's reproductive choices be shaped by the availability of yet another "option" for fetal treatment? How will women's reproductive autonomy and health be protected and safeguarded? Can women really "choose" fetal surgery, a practice which asserts fetal patienthood, at precisely the historical moment when a woman's right to choose abortion is seriously threatened? How will access to fetal surgery be shaped by race and class? Whose fetuses will be considered worth saving? This dissertation thus raises important questions about the contexts in which women can and do make reproductive decisions.

Fetal surgery thus presents an important challenge for women's health policy where questions of resource allocation are critical. In a nation obsessed with health care costs, fetal surgery is an expensive operation at an average cost of around $25,000. As an *experimental* procedure with fetal mortality rates of 50-60% (depending on the operation), this seems a questionable expenditure of federal health care dollars. Is it worth spending huge sums of money to "save" a few fetuses while

many women cannot obtain adequate basic prenatal care? One-quarter of all women who gave birth in 1990 had no prenatal care in the first three months of their pregnancies (Gold and Richards 1994). Compared to women who have access to prenatal health care, women who do not are twice as likely to have low birthweight or premature babies. These numbers are comparatively interesting given that fetuses which survive fetal surgery must undergo additional treatment after birth and may have chronic health problems throughout the rest of their lives, suggesting that "saving babies" is a relative concept.

Examining fetal surgery thus focuses attention on some key issues regarding collective national responsibility for healthy babies. Fetal surgery represents high-tech, high-cost treatment of a limited range of anatomical birth defects. It is cowboy surgery on the final frontier, and it is fraught with danger. It also represents a stark contrast to *prevention* of birth defects which would require quite different federal expenditures. Investing in basic prenatal care for all women would surely "save" more babies than fetal surgery currently claims to. It would also send a different kind of cultural message about national commitments to women's health. Where fetal surgery represents a potential threat to women's health and well-being solely for the benefit of fetuses, basic prenatal care is an investment both in fetuses *and* in pregnant women. As Leigh (1994:185) points out, "*Infant* mortality reflects not only the standard of living of a population but also mirrors the health of the mother." Thus, health policies emphasizing prevention rather than technological fixes would contribute both to fetal and maternal health, and would serve as potent reminders that healthier babies and moms should be a collective social responsibility.

The Sociological Imagination Revisited

I want to conclude my story of fetal surgery with a return to the sociological imagination (Mills 1959). Throughout the duration of this research, when I explained

to people what my work was about, a common response was, "Wow, that's really great! I didn't know they could fix babies in the womb." These reactions surprised and disturbed me, for they seemed to erase the social context. I had expected everybody to be aware of the contradictions posed by fetal surgery in a context where fetuses are so contested. As I began patiently explaining my work--filling in the contours of the practice, showing how social context matters--awareness would gradually dawn in people's eyes. They would exclaim, "Well, I never thought of it in quite that way." This dissertation has been about rupturing the blind faith with which most people confront cutting-edge medical "advances." To paraphrase Mills, I have attempted to use social structure with sensibility and to trace linkages among a variety of milieux. My task has been to make people *see* fetal surgery in different ways, recognizing its sociological implications beyond the operating room.

Yet this dissertation has not been about simply describing the social and political contexts within which fetal surgery has emerged. Rather, I have tried to show how reproductive politics have *permeated* the very fabric of medical work, profoundly shaping fetal surgery and its work objects. Fetal surgery is not merely affected or impacted by reproductive politics; it is inextricably linked to politics through material and symbolic properties of fetal work objects. Because human reproduction has been among the most contested social problems historically, fetal surgery, infused with reproductive politics, is also a social problem. Although serendipity has been an important component of this story, it is not an accident of history that the social debut of the unborn patient coincides with increasing social and political ferment around abortion. The emergence of fetal surgery and medical investments in fetal patienthood are consistent with other types of investments--cultural, political, economic, and scientific--in human fetuses in the U.S. at this particular historical moment.

What if it *were* possible to erase or transform the social context of fetal surgery? We could, for example, imagine a world (certainly not Atwood's theocratic

Gilead) where operating on fetuses was simply a heroic medical technique devoid of political content. All women would have access to a range of prenatal care, including basic services *and* high-tech fetal treatments. Of course, clinical implications for women's health would likely still be salient given the embodied nature of pregnancy. But this is a rather pointless exercise because, as this dissertation has shown, content and context are mutually constitutive and inextricably linked. They are interchangeable analytically, and both matter in what counts as medical knowledge and practice. We should care about fetal surgery because it embodies many of the potent contradictions we live with every day: amazing medical feats, the limits of technology, maternal/fetal conflict, heroic moms, contested fetuses, and politicized reproductive decisions. Rather than imagine brave new worlds (Huxley 1932), we should instead use our sociological imaginations to understand the diverse and contested meanings of fetal surgery and the making of the unborn patient in the present. It is here, in the meaning-laden worlds of biomedicine and reproductive politics, where the implications of breaching the womb are proliferating.

Epilogue

"WHITHER FETAL SURGERY?"[1]

"Although a good deal has been learned about fetal conditions that are more or less amenable to open surgery and there have been some successful outcomes, it does not seem likely that the existing technology offers an approach that will save large numbers of endangered fetuses."
(Institute of Medicine 1994:38)

This dissertation has presented an historical sociological analysis of the emergence of a new biomedical specialty. Fetal surgery has been emerging and consolidating for the past two decades, but it has yet to attain a final, stable shape. Because its future is uncertain, it is virtually a blank slate upon which participants can (and do) inscribe any future they wish. It seems appropriate to conclude with a brief preview of the future of fetal surgery as predicted by some of my informants, among whom opinion has been mixed as to its future success. Proponents extoll the virtues of fetal surgery and predict a useful future, while critics decry its excesses and failures and consign it to the biomedical trash heap. Even my account of fetal surgery is affected by this ferment. Fetal surgeon Jack Nelson once told me, "You better hurry! You're trying to do a dissertation on a very dynamic field right now. This is not a static field. If you don't finish it in a year, it will be old stuff." In part, this temptation to predict the future may be particularly salient with experimental procedures which have not yet become routinized in practice. Somewhere along the path between experimental and routine treatment, whither fetal surgery?

In 1966, Adamsons (1966:204) outlined the perceived major benefits of the nascent specialty of fetal surgery. The most significant advantage, he claimed, was

---

[1]See Louw (1974) for a discussion of the future of pediatric, including fetal, surgery. The misspelling of *whither* as *wither* in his title is deliberate.

"direct exposure of the fetus after hysterotomy." He went to to discuss experimental clinical work in Puerto Rico and New Zealand that had established important precedents in fetal surgery. Yet, despite its promise, Adamsons was entirely convinced that fetal surgery had a broad future. He (1966:205) wrote, "It appears unlikely that even in the distant future, fetal surgery will become a field of major concern to the clinician since most abnormalities requiring surgical correction can be dealt with after birth...For the present, the sole use of fetal surgery is in the treatment of erythroblastosis fetalis [Rh disease], and even here its value is still open to debate. Nevertheless, the acceptance of the concept that diagnosis and even surgical treatment can be extended to prenatal life is an important advance. It paves the way to a more complete understanding of the environment that will ensure optimal prenatal development."

Louw (1974) was more optimistic, predicting that fetal surgery would have a place in the future as a treatment for a range of congenital defects, including diaphragmatic hernia. He called for intensified efforts in fetal treatment and perceived the surgical approach as an opportunity with great promise. He (1974:1597) argued that pediatric, or fetal, surgery "should not stop at neonatal nor fetal anomalies, but maybe start tampering with embryos, removing a gene here and implanting one there...forever striving to improve the quality of life." With these words, he presaged one of the major trends occupying the contemporary wave of fetal surgeons: prenatal gene therapy.

Like Adamsons and Louw before him, Pringle (1986) also reflected on the past and future of fetal surgery. He described the historical efforts of the 1960s in New Zealand and Puerto Rico, pointing to what had been learned from these activities. He argued that fetal surgery might have become more prevalent in the 1960s had Liley's group not been so successful with closed operative techniques for fetal exchange transfusions. Detailing some of its problems and achievements, Pringle forecast the

future of fetal surgery in optimistic but cautious terms. He (1986:25) wrote, "At present, fetal surgery is limited in its scope but very widespread in its application...The results of these procedures are variable but fetal salvage may not have been greatly increased." For improved outcomes, he predicted the development of better tocolytic agents and methods for diagnosing which fetuses to treat. He (1986:29) closed his predictive account with these words: "Fetal surgery has a proud history, an exciting present and a promising future. The aim of pediatric surgeons should, indeed, be to 'improve the quality of life'...Fetal surgery will be just one of the means at the disposal of the medical profession to do just that."

Twenty years after his initial predictions, Karliss Adamsons has retained his enthusiasm for the promise of fetal surgery. His eyes sparkled throughout our interview and he showed a lively interest in the goings on at Hilltop Hospital. He expressed admiration for the fetal surgeons at Hilltop, "who have managed to remain excited about their work despite very high mortality and morbidity." He wanted to know, for example, how the fetal surgeons in my study view their contributions to the field in terms of time and money allocated. He remarked, "In the U.S., we're willing to invest lots of money, time, and resources to save one life. The work at Hilltop is showing that we can salvage an organism that would otherwise die. Many societies would consider fetal surgery excessive, but we're a wealthy society. Resources are misused in many ways already, so why not pursue something like fetal surgery?" Adamsons also thinks fetal surgery is worthwhile because it "teaches us about basic mechanisms and not just technological innovation. What fetal surgery has contributed to is a breakdown of the belief that the uterus is sacrosanct. It has basically helped the construction of the field of fetal medicine."

Vincent Freda is also optimistic about the future of fetal surgery, predicting that surgeons "will probably do more cases. It will become more common." He feels that "if people go back and read what I wrote, they'll realize what can be done." He

also believes that the field will expand to include, for example, cardiac surgery and prenatal gene therapy. He, too, asked me about Hilltop Hospital, commenting that surgeons there "didn't cite me properly, probably because of jealousy." When I told him in general terms about conflict among different specialists, he remarked that there were very few interspecialty tensions at Columbia in the 1960s. The patients were "his" and the grant money was Adamsons', and cooperation was essential to accomplishing anything. As for who should be involved in fetal surgery at the present time, he stated: "The pediatrician should be the surgeon for the fetus. The obstetrician should open the mother and take over after fetal surgery. There should be collaboration. Frankly, the obstetrician doesn't know his ass from his elbow about doing surgery on a fetus. So the OBs should only open the abdomen and put the baby outside, and then the pediatric surgeons should take over and do the rest. But the OBs should then close up the mother."

Graham Liggins, who worked closely with William Liley in New Zealand, is somewhat guarded about the future of fetal surgery. He told me, "It's highly controversial, for one. In my view, fetal surgery is not going to be generally useful until we have a better understanding of the mechanism of the control of labor. To that extent, the work at Hilltop Hospital and my work are, you might say, intertwined. But we've still got quite some time to go before we'll be in a position to successfully control factors such as preterm labor and hormones. In general terms, though, I could see the future of fetal surgery being in endoscopic techniques, where you have direct vision into the uterus through a fiberoptic scope."

Predictions made by Hilltop Hospital's cast of characters are also particularly rich. For example, Jack Nelson told me, "We've done amazingly well just to have gotten this far...Now we're understanding the effects of surgery on physiology, and the ultimate outcome will be that we're able to improve everything. It's going to happen shortly...The fetal surgery enterprise will not die because there are a number of other

groups starting it now. And they're starting it after discussions with all of us and incorporating a physiologic point of view...It will continue and it will grow; it's just going to take time." Nelson concluded by echoing Liggins and remarking that "endoscopic surgery is the wave of the future. It's less interventive because it's done using needles and thus does not require open surgery. Also, it could potentially be used in the future for non-terminal fetal conditions."

Stephen Graham is very enthusiastic about the future of fetal surgery, but told me that he hopes that the specialty will grow slowly. In retrospect, he feels that fetal surgery "could have been immensely controversial" (rather than just somewhat controversial). But because the initial participants "laid low and didn't go public right away, fetal surgeons were never crucified the way cardiac transplant surgeons were." Participants "never wanted fetal surgery to be a circus," and they were "very careful about not saying things publicly until they had been peer-reviewed and published." He foresees a time when fetal surgery will be used for all kinds of fetal defects, including routine diaphragmatic hernias. Yet the "Achille's heel" of fetal surgery, preterm labor, will continue to haunt the field. Graham predicts that fetoscopy and endoscopic surgery will "take off," remarking that "the best fetal surgeons of the future will be kids who are really good at video and computer games. Newer techniques will require micro-manipulations." He also raised the possibility of fetus-to-fetus transplantation and prenatal gene therapy as waves of the future.

Tony Murphy described the future of fetal surgery in terms of early reactions to his work: "I distinctly recall a major pediatric surgery meeting where I presented the natural history of congenital cystic adenomatoid malformation, this was in 1984. I suggested that one consideration might be to treat before birth. And there was like no discussion, absolute silence. And so, you just keep working away. Then last week I chaired a course in fetal diagnosis and therapy, and there were about 200 folks there just to watch and learn. It was an interesting contrast; it was almost like being

legitimate. The upshot is, no one knows ten years from now whether we'll be doing much open fetal surgery. I don't know. But the enterprise of the fetus as a patient, treating the fetus as a patient, is here to stay. No question about it, whether it's gene therapy in the future or whatever. It's here to stay."

Joseph Sigler feels that not just the fetal patient but "fetal surgery itself is here to stay." He told me, "Certainly until such time as we are able to avoid all these defects. But I think there are many aspects of this that are important. I think you have to get into the issue of why you would want to operate on a fetus. It's not because the lesion the fetus has is necessarily life-threatening during fetal life. Some of them are, but others are not...In a number of lesions, the presence of one defect results in secondary changes in other parts of the body...If one could correct the lesion before birth, one could avoid that development. This is the reason why there is the appeal of going to fetal surgery." When I asked him about the success of fetal surgery, he remarked "I think that they're getting closer to the goal, but it's quite a ways before they solve all the problems. One of the problems we have to face up to is the fact that they have operated on babies relatively late in gestation. I think what we have to aim for is to diagnose these things earlier and to consider doing something earlier as well." Sigler, too, raises the specter of endoscopic and prenatal genetic therapies as waves of the future.

Donald Truitt has also maintained enthusiasm for fetal surgery: "I think we should continue to push on with it. I'm not sure of the direction we should push, but we should clearly continue to push...Untreated cases have a very dismal outcome; we're seeing about 60% of these fetuses die as newborns. You can say, well, that's the name of the game and we're just going to have to accept that fetal surgery is not going to be as successful as we'd like it to be. Maybe that's true. I would very much like to say I know the answer to that question, sitting here today. But I'll tell you, if the answer turns out to be no, fetal surgery can't do it, then we have to accept

something that I find to be sad." He also placed his opinion in historical context, remarking "Who would have ever thought to operate on a fetus to fix up an abnormality? It seems perfectly logical to do now." As with other commentators, Truitt believes that endoscopic techniques present great promise to the field.

Karl Hansen is also optimistic about the future of fetal surgery, drawing an analogy with the space program. He stated, "The ultimate goal was to put somebody on the moon, which we did, but there were a bunch of incredible things that came out of it just by looking at related topics. In fetal surgery, the discovery of scarless healing is a major benefit. Even if the ultimate end of fetal surgery is no fetuses ever get operated on, I think that the process of the research is going to have beneficial effects for health care as a whole. But I do think that there will be a prominent place for fetal surgery in the future." Yet Hansen also feels that open surgical techniques will be replaced by prenatal gene therapy. He told me, "I think gene therapy is the wave of the future. It's amazing, it's perfect. There is very little intervention to both the fetus and the mother, and the benefits are incredible. A lot of these big terrible diseases are just missing one amino acid, or change in one amino acid, or missing one gene sequence. And you end up with a whole cascade of abnormalities. If you can just replace that in utero, you know it's something that will be easy, safe, and inexpensive. I think that's what will happen."

Barbara Greenwood is less optimistic about the future of fetal surgery. She told me, "The womb is the last frontier in medicine. I'm not sure there are other frontiers, maybe the genes. But in terms of human anatomy, I think that there's really no other area that's been sacrosanct like the womb and the developing fetus has. And I think ultimately they'll probably conquer it. As for fetal surgery, I think there will be some continuation of the C-CAM stuff, but I have my doubts about the other stuff. I don't know how many more moms and babies we can bring up to the altar of fetal surgery with the outcomes that we're having."

Walter Siegel, like Greenwood, is not very enthuasiastic about fetal surgery's future success. He remarked, "Mortality data based on thirty cases is not good, with only four surviving fetuses. I don't think any of us would consider this to be a great success...With the success, or lack of, with these procedures, you can't really counsel a woman to have surgery...There are very few fetuses for which this will be appropriate, and very few indications where this will be useful because you can't get there early enough. Whereas this is very sexy, it's not very practical. I don't think we're going to save many fetuses." Yet the future of non-surgical fetal treatment appears to be rosy, and Siegel predicts that prenatal gene therapy will eventually be widely used.

While it is tempting to just let the data speak for themselves, these accounts embody many of the themes that have appeared in this dissertation. What are we to make of these diverse opinions about the future of fetal surgery? Do they represent merely an extension of the interspecialty differences discussed in Chapter 5? For fetal surgeons, the future certainly seems bright, while obstetricians and social workers are more cautious and critical. Yet the future of the specialty, as all of these informants make clear, is intimately tied to issues related to accessing the fetal patient. Preterm labor is still, twenty years after Liley's pioneering efforts, seen as the most significant obstacle to successful open fetal surgery. Ironically, many of these informants advocate a 180-degree turn back to closed techniques in which the womb remains intact, such as endoscopy and prenatal gene therapy. The tools of the future may well be fiberoptic scopes and genes, manipulated by a generation of surgeons trained on video and computer games. Having been ushered into the world through open surgery, the fetal patient can now be legitimately approached through other means. The future of fetal treatment, it seems, may not involve surgically breaching the womb after all.

Appendix A

METHODOLOGICAL STRATEGIES AND QUANDARIES

"There is no way in which any social scientist can avoid assuming choices of value and implying them in his [sic] work as a whole...No one is 'outside society'; the question is where each stands within it."
(Mills 1959:177, 184)

"My only advantage as a reporter is that I am so physically small, so temperamentally unobtrusive, and so neurotically inarticulate that people tend to forget that my presence runs counter to their best interests. And it always does. That is one last thing to remember: writers are always selling somebody out."
(Didion 1968)

In social, cultural, and feminist studies of medicine and technoscience, we often take great pains to elucidate and critique the underpinnings of these practices. We seek to show how and why scientists, doctors, engineers, and other workers in these elite fields do the things they do. We look over many different shoulders (sometimes cold ones) in our eager attempts to interpret and portray their social worlds. In doing so, careful attention is paid to work activities and concrete practices, what we might term the "nuts and bolts" that different actors use to fabricate elements of the natural world into patients, facts, and technologies. It seems only fitting that we should turn our analytical lenses back upon ourselves. We need to be reflexive about how (and why) we construct our accounts of others' experiences (e.g., Rosaldo 1989). We need to assess our tools and methods of knowledge production, and think critically about whom we are accountable to in our analytic practices. We need, in short, to identify and elaborate upon our own nuts and bolts as we critically engage the work of others.

Such reflexivity may seem, to some, to be mere navel-gazing or yet another foray into the confusing and amorphous black hole of postmodernism. Yet critical attention to methods, our own as well as others', brings into relief some important

issues in social and cultural studies of medicine and technoscience.[1] Such attention raises the question of whether there is something qualitatively different about studying doctors, scientists, and engineers than there is in studying, for example, teenagers or drug-users. When we "study up," or study those with *more* power than we have, do we need to think about methods in a different way? For example, how do we gain access to clinical and scientific settings? Upon what factors is our continued access contingent? Do we need to worry so much about adequately and ethically representing our informants' experiences when they already speak with considerable authority? What happens when what (and whom) we study is controversial? To whom *are* we accountable in our research? All of these issues surfaced in my study of experimental fetal surgery, often prompting considerable methodological, ethical, and personal soul-searching about this project.

Thus, having spent so much time and energy attempting to understand work objects in fetal surgery, I wanted to examine my own work object, this dissertation research, in a critical and reflexive way. During the four years since I began data collection, I have been confronted at every turn with methodological challenges. Some have been met with creative strategies, while others have remained quandaries. Below, I explore the methodological nuts and bolts which I used to lovingly, arduously, and sometimes frustratedly construct this dissertation. I first describe my data sources and methods. I then explore in more depth three related issues germane to this research which I found particularly daunting: 1) problems in pursuing a controversial topic; 2) challenges of "studying up"; and 3) issues of accountability. This appendix is not meant as an apologia for what I did or did not do in my

---

[1]In her insightful methods appendix, Anspach (1993:177) writes, "In field research there is another type of decision, far more subtle and perhaps less consciously reached, for which the canons of the 'scientific method' provide few guidelines. These concern such matters as what to observe, when to observe, whom to talk to, what to ask (and *not* to ask), how to record information, what information to record, what to believe, what to question, what to delete, and what to present to the reader. These decisions are frequently oriented to the contingencies of the moment and guided not by scientific rules of procedure but by considerations of ethics, etiquette, politics, pragmatism, and 'presentation of self.'"

dissertation; rather, it is designed to provide some insight into some of the choices I have made (or felt compelled to make) in crafting the final project.

Data Sources

I drew on an array of both primary and secondary data sources in researching this project: semi-structured interviews; ethnographic observations; historical archival research; scientific and clinical literature; videos; and popular cultural representations.

Interviews. Between November 1991 and December 1994, I conducted formal, semi-structured interviews with sixteen informants, including fetal surgeons, sonographers, obstetricians, social workers, fetal physiologists, laboratory coordinators, and patients. For historical research in New Zealand, I also interviewed family, friends, and colleagues of William Liley. In Puerto Rico, I interviewed Karliss Adamsons and Arsenio Comas. Formal interviews were audiotaped and transcribed for subsequent coding. Further, throughout this project I have informally talked with many informants, including neonatologists, nurses, geneticists, genetics counselors, other specialists, and administrative staff.

Ethnographic observations. Between October 1991 and November 1993, I conducted ethnographic research in a variety of settings. First, I observed four surgical operations on human fetuses performed at Hilltop Hospital. Shortly after I began my research, the Fetal Treatment Unit initiated a rule prohibiting non-critical personnel from being in the operating room during fetal surgery. This was largely in response to intense interest generated by fetal surgery which resulted in up to 15 *non-essential* people in the OR at any given time. All of my observations of fetal surgery have thus been conducted from a vantage point in sub-sterile rooms adjacent to the operating rooms, with occasional peeks into the OR for richer data. I was often kept company by other observers such as a visiting nurse from Redwood City, a surgical resident from Spain, and many others. Being required to wear surgical masks made

the experience at least somewhat more authentic. Despite this somewhat awkward viewing situation, every surgery is videotaped and the image is transmitted in real-time directly onto a television monitor in an adjoining sub-sterile room, providing a bird's-eye view of the surgery. Unfortunately, the sounds and smells of the OR are lost in this medium.

During this period, I also routinely attended and observed weekly staff meetings at Hilltop Hospital in which many participants in fetal surgery discussed specific cases. From these meetings, I generated voluminous fieldnotes about participants' interactions and about specific cases. In addition, I was present at ad hoc staff meetings organized to discuss particular problems and topics, such as preterm labor.

Last, I attended several formal, clinical presentations about fetal surgery, both within the institutions where I conducted my fieldwork and at other sites. These included, for example, Ob/Gyn Grand Rounds, brown bag lunches, and other forums at Hilltop Hospital. Also, in June 1993, I attended an Institute of Medicine conference on "Fetal Research and Treatment" at the University of California, Irvine. A number of presentations at this conference focused on experimental fetal treatment applications (Institute of Medicine 1994).

Historical archives, papers, documents, and records. An important component of this dissertation research was an emphasis on historical sources. In New Zealand I analyzed the papers of the late Dr. William Liley. These were not formally archived, but rather "collected" in the dusty, dark attic of National Women's Hospital. Part of my research involved lugging heavy boxes covered with dust and cobwebs down to my office, often sharing the elevator with curious patients and staff. The papers included correspondence, clinical notes, laboratory records and reports, hospital protocols, patient records, unpublished and published articles, copies of lectures and presentations, and reprints of articles on specific topics. In Puerto Rico I analyzed the

published papers of and interviewed Dr. Karliss Adamsons, currently Chair of the Department of Obstetrics and Gynecology at the University of Puerto Rico in San Juan. At Hilltop Hospital I reviewed a handful of non-confidential records, such as memos, correspondence, informed consent documents, and copies of grant proposals relevant to the historical development of the specialty.

Scientific and clinical literature. There is a growing body of literature dealing with physiological and clinical aspects of fetal surgery, including scientific aspects, technical issues and developments, clinical problems and their management, morbidity and mortality data, future research directions, and issues and problems associated with the fetal patient. The most famous of these publications is *The Unborn Patient* (Harrison, Golbus et al. 1991), considered the major text in fetal surgery and edited by three key actors responsible for the emergence of fetal surgery in the early 1980s. The book contains a wealth of scientific and clinical data and has proven useful to me in better understanding and critiquing the science and practice of fetal surgery. Given its prominence and association with a key research site, the book also provided the basis for the somewhat ironic title of my dissertation, *The Making of the Unborn Patient.*

Videos. Every fetal surgery is videotaped for research and recording purposes. Hilltop Hospital has produced an informational video for prospective patients using some of the recorded video images. I obtained this video, *Fetal Surgery: Options, Risks, Decisions*, and analyzed it in terms of its images and content. I also have videotapes of presentations by key informants at forums such as Ob/Gyn Grand Rounds and a videotape of a March of Dimes commercial for fetal surgery. These videos were all transcribed and analyzed using modified content analysis and grounded theory methodologies.

Popular culture. Following a period of secrecy surrounding the emergence of fetal surgery, in recent years this practice has moved into the public eye as a sort of technocultural curio. *New York Times* science writer Gina Kolata has published

numerous articles about fetal surgery and a book called *The Baby Doctors* (Kolata 1990). Although Kolata's perspective is hagiographic rather than analytic and critical, the book nonetheless contains rich and fascinating data from interviews, observations, and research. In addition to this book, fetal surgery has been the topic of numerous news/entertainment television shows, such as *20/20* and *Hard Copy*. I obtained transcripts and videos from some of these feature shows and analyzed them as secondary data.

Methodological Strategies

This is a qualitative dissertation based on my analytical interpretations of the experiences and activities of my informants and related materials. By immersing myself in the worlds of experimental fetal surgery and its inhabitants, I attempted to grasp the culture(s) of these worlds, including work activities and their meanings. My goal was to develop original theoretical concepts based on empirical work. Thus, my analysis adhered to the general principles of grounded theory (Strauss 1987; Strauss and Corbin 1990). In this perspective, focus is on the social processes and conditions which undergird and sustain the phenomena in question. Data collection and analysis proceed simultaneously, and initial theoretical concepts are continuously modified to better reflect and interpret the data. The resulting written account integrates the theoretical concepts into a framework which explains and interprets the phenomena under investigation. Throughout this project, I coded fieldnotes, interviews, and other data according to grounded theory principles.

Guided by the broader analytical perspective of grounded theory, I utilized a range of qualitative methodologies for data analysis such as informal and focused in-depth interviewing, field research, ethnographic observations, textual and visual content analyses, some interpretive life histories, and other approaches as they became salient. By using such a diverse set of methodological tools, I attempted to

achieve triangulation (Denzin 1989) and a richer, more comprehensive analysis of the data. In part I used these different methods because I drew on so many different data sources. I tailored each method to an appropriate data source. For example, while ethnographic observations were clearly the right choice for data collection in the operating room and at staff meetings, I needed a different approach for analyzing videos. Thus, heterogeneous data sources led me to explore a number of different and sometimes innovative methodological strategies.

In addition to grounded theory, my research was also informed by the interpretive interactionist approach of Denzin (1989, 1992). In this framework, communication and cultural forms are seen as central to processes of interaction, biography, and social structure. Or, as Denzin (1992:27) points out, "the personal and the structural are mediated through the process of communication. This process is connected to the world of cultural meanings." This emphasis on culture is critical in any attempt to understand the meanings associated with fetuses in the U.S. at this particular historical moment in which fetuses and uterine spaces are highly contested. While not explicitly following Denzin's methodological rules, his approach sensitized me to the importance of cultural meanings within the world I studied. My concept of *work object* was in part formulated to capture a sense of the traffic between cultural politics and biomedical practices, with fetuses positioned as material and symbolic conduits for communication and interaction among the many participants in these worlds.

I also borrowed from feminist epistemological and methodological frameworks (Fonow and Cook 1991; Olesen 1994). Drawing on what Balsamo (1990) calls the "feminist sociological imagination," my dissertation problematizes women's experiences within experimental fetal surgery. Throughout the dissertation, I labored to show how pregnant women are shaped by work practices in fetal surgery. While not always considered central actors in this domain despite their *engaged* participation

in this work, pregnant women are always *implicated* actors. Not only are the women in fetal surgery simultaneously working subjects and work objects, but fetal surgery has potentially major consequences for women's reproductive health and lives. I approached this issue by paying especially careful attention to how pregnant women were represented in the data, even where they were made virtually invisible by and within the practices I studied.

Guided by the above frameworks, I began with basic coding of data which yielded salient and recurrent themes such as constructions of pregnant women and fetuses as work objects, uses of technology, clinical decisionmaking, cooperation, conflict, and so on. As these themes emerged through the constant comparative method (Glaser and Strauss 1967), I found connections and linkages among different codes. I then moved on to an axial coding strategy to make sense of the increasingly dimensionalized nature of my data. Here I began to focus on relationships among phenomena, such as how fetal constructions are shaped by conflict among medical workers or how technology impacted the emergence of fetal surgery.

As the body of data began to grow through continued collection, both the significance and the difficulty of linking data became obvious. Fielding and Fielding (1986) provided some helpful hints about linking categories, and enabled me to integrate a temporal and processual aspect into my analysis. Linking the many codes that emerged through grounded theory techniques was a useful strategy in that it permitted an analytical structure within which to make sense of the data. Where initially I had descriptive codes, axial coding and the linking strategy enabled me to conceptualize my data in broader terms. The elaborated categories of codes and their relationships proved to be highly flexible, enabling me to understand and articulate the complicated dynamics of experimental fetal surgery in valid and adequate ways.

As an example of how this methodology unfolded in practice, I discuss the coding process for *conflict*. This is a particularly interesting code as I had not

anticipated conflict when I first entered the field. In other words, I was not looking for conflict in this domain; it came to me as an analytic category through its continual reoccurrence in my field site. The code's first appearance in my data was in the fall of 1991, shortly after I began fieldwork. At a staff meeting, medical workers were discussing an unsuccessful operation which resulted in fetal death. As they spoke, they began to argue and disagree with each other. The death of the fetus seemed to magnify underlying tensions among different specialists involved in fetal surgery. I coded this dynamic as *conflict.* As the meeting continued, workers began to assign *blame* to each other for the fetal death. As my fieldwork progressed and I attended subsequent meetings, I began to notice that conflict was ubiquitous, appearing in my data numerous times. I also noticed that it was connected both to *failure* and to *blame*, and that medical workers often used language of conflict when they described their relationships with one another. As my body of data grew, I began to conceptually link these different categories to form a picture of how failures are dealt with in this domain and how conflict manifests in intraprofessional interactions.

In short, I used a range of methodological strategies to research and analyze the making of the unborn patient. The different frameworks and tools I drew upon were articulated together under the broader aim of developing original theoretical concepts to explain social processes in this domain. My concept of *work objects* was built up out of empirical research, in which I used grounded theory techniques to dimensionalize this concept and situate it within the conditions of its origins. It became clear to me early on that actually *working on* fetuses was a significant analytic point with profound repercussions in this domain. Grounded theory, supplemented by other methodological approaches, enabled me to identify and describe how medical work and the politics of reproduction have mutually shaped fetal and maternal work objects and the emergence of fetal surgery as a new biomedical specialty. Yet I ran into a number of problems with this research not easily settled by choosing a certain

methodological strategy. I think of these as my methodological quandaries, discussed next, fond sources of many sleepless nights.

Methodological Quandaries

In any research project there are bound to be methodological dilemmas, some of which may be quickly resolved while others linger long after the project ends. Qualitative research, in particular, often seems to result in sticky situations, most likely because qualitative approaches place the researcher in close proximity to her informants. We interact on a regular and sometimes even intimate basis with those we study, often spending large amounts of time in their presence. We develop meaningful and sometimes problematic social relationships with our informants. There is a large literature dealing with the complex nature of qualitative research (Kleinman 1991; Denzin and Lincoln 1994). Here I focus on three issues which are especially relevant to this research: controversy, studying up, and accountability. In many conversations with colleagues doing similar work, I have learned that I am not the only researcher to stumble around in these methodological brambles. My intent here is not to definitively resolve these dilemmas. Rather, my aim is to raise these issues as pertinent to qualitative studies of medicine and technoscience.

Politics, Politics Everywhere: Issues in Researching A Controversial Topic

My analysis is not the first in social and cultural studies of medicine and technoscience to explicitly and knowingly focus on a contested issue (Nelkin 1984; Clarke 1990; Clarke and Montini 1993). What I want to do here is discuss *methodologically* how the contested nature of what I studied shaped the processes and products of the research. A key component of this research was to show how the politics of reproduction have permeated experimental fetal surgery since its inception. Yet like fetal surgery, my research also exists within a specific historical, social, and

political context. The nature of this topic, and my desire to engage fetal surgery and its practitioners seriously, guaranteed that I would become politically involved. Reproductive politics have been my constant companion since I began this project, and indeed have shaped the kinds of questions I asked about this topic.

I have thus spent a great deal of time and energy articulating the ways in which fetal surgery and its practitioners are political. Yet throughout the duration of this project, I have also had to be reflexive about my own politics and how they have shaped this research. As Mills (1959) argued, "there is no way in which any social scientist can avoid assuming choices of value and implying them in his [sic] work as a whole...No one is 'outside society'; the question is where each stands within it." My deep commitment to women's health issues and my own reproductive rights philosophy generated my concerns about fetal surgery in the first place. Having begun this project, simply "turning off" my politics was not an option. To assert that I could somehow manage to keep my politics separate from my research, while simultaneously exposing my informants' politics, would have been the height of methodological hypocrisy. Politics are everywhere around us, and science--our own and others'--may well be politics by other means (Latour 1988). There are no pockets of neutrality in social life. Thus, the question was never, would my work be political? Rather, the questions were, *how* would it be political and how political would it *be*?

Having acknowledged my politics, I thought it would be relatively easy to integrate them into my research. Initially I figured I could simply ask a bunch of questions about reproductive politics, particularly abortion, and go from there. Unfortunately, my informants had other ideas and demonstrated some unexpected resistances. Many of them, especially fetal surgeons, actually appeared uncomfortable when asked to discuss abortion politics. Their usual oratorical grace and authority seemed to desert them in these moments. Other informants seemed more than willing to discuss abortion, but cheekily demanded to know what *my* politics

were. They did not seem to realize that *they* were the informants and *I* was the researcher supposedly immune from nosy probing! Depending on the company, I either would or would not discuss my politics in depth. The decision was centered largely on whether I felt "safe" with an informant, that is, safe to disagree. Yet if I did not voluntarily disclose my politics or if they did not ask, I was left with a nagging sense of guilt that I had somehow duped my informants.

This type of situation was rare, however, because it is challenging to discuss fetal surgery without some reference to reproductive politics. For example, very rarely did an interview end without a discussion of abortion and its relationship to experimental fetal surgery. Most often I raised these issues, but sometimes an informant did so first. Even when I initiated the discussion, I was never stonewalled by my informants on this topic. For a number of reasons, discussed previously, contemporary fetal surgeons assert that their work has very little to do with abortion. Yet when pressed, they acknowledge that reproductive politics are central and that fear of their work being publicly linked to the ongoing American abortion controversy prompted the initial secrecy surrounding their activities. One clinician active in fetal research had an unusually sophisticated understanding of the ethical and social issues undergirding fetal surgery. He remarked, "I'll tell you a truly interesting ethical problem...We have ten surgeons in this lab whose only focus the majority of the time is the fetus as a patient. We have obstetricians...We have anesthesiologists...Multiple nurses...We're all operating on fetuses, trying to do our best to protect them, yet when we're done with the operation that fetus could still be legally aborted."

These are the kinds of contradictions that many people I interviewed live and work with. Yet many (but not all) preferred to gloss them over in their accounts of fetal surgery. For example, I met with a consultant, Peter Quinn, hired to help the fetal surgery group at Hilltop Hospital develop an historical "insider" account of the

specialty. The proposed book will be both textual and visual, containing images drawn from videotapes and photographs of surgery. Quinn told me that the Fetal Treatment Unit had been offered $10,000 by Bernard Nathanson, a major anti-abortion figure, for some of their images. In particular, Nathanson wanted an image of a tiny fetal hand extending out of the womb. The fetal surgery group turned down his request, but they plan to use that same image and many others in their book. Quinn went on to say that the fetal surgeons want the book to be an "objective" account that will "not take sides" in the abortion debate. Mostly they "don't want it to be a manifesto for the right-to-life folks." At this point, I interjected with a suggestion that perhaps this view was politically naive. I pointed out that regardless of their "benign" intentions, once the book is in the public domain it will be used by anti-abortion groups and possibly others for various instrumental purposes. In short, I reminded Quinn that the Fetal Treatment Unit's work, including its cultural dissemination, does not exist in a vacuum, devoid of political content and context. Rather, it is profoundly political.

A related issue is that I was often told that I was seeing politics where none actually existed and that my own perspective was coloring my findings. (I certainly hoped so, but wondered if this was analytical impertinence on my part.) One informant told me that it was okay to have a critical perspective on fetal surgery (she herself confessed to having one), but that as a sociologist I should strive to be "objective and balanced." That I was perceived not to be objective by some informants tinged my research with a patina of illegitimacy. Yet other audiences assumed from the outset that I did have a political commitment at stake, and I was routinely asked by people what my particular stance was. I eventually developed a stock answer along the lines of, "I don't really think fetal surgery should be going on for a whole set of complicated reasons, which you can read about in my dissertation."

There was almost no relief from these dilemmas, either. As I excavated contradiction after contradiction from the layers of experimental fetal surgery, I found

that I, too, was uncomfortably embedded within them. On some occasions I could discuss such contradictions directly with my informants, while other times I felt almost paralyzed by these dilemmas. One informant, sensing my deep political anxieties about fetal surgery and its relationship to reproductive politics, told me that "we're constrained by the Judeo-Christian framework...If you put it in a biological framework, everything becomes pretty clear." Had I only known that a return to Science would have resolved these contradictions, I might simply, à la Gertrude Stein, have accepted that a fetus is a fetus is a fetus. But I knew in my sociologist's heart that a fetus is a work object is a political quagmire. Therefore I continued my quest to articulate the linkages between the medical work of fetal surgery and the complicated and contradictory politics of reproduction.

Not only did I need to worry about integrating my politics into the actual research, but I became increasingly concerned about the reception afforded my work in different contexts. Among women's health and reproductive rights activists, my work is regarded for its political content--which, I think, says something about how well I have integrated my political and academic passions. Yet other audiences have been more wary of my research, not only because of its political implications but also because of the contemporary political context. For example, I was honored to receive a doctoral dissertation improvement grant from the National Science Foundation, which made possible my research trips to New Zealand and Puerto Rico. Yet I was both amused and irked to learn that the agency had changed the title of my project, deleting the word "fetal" and leaving the impression that I was doing an historical sociology of all of experimental surgery. Quite a task that would have been! (And had that been the task, I would certainly have asked for more money!) Last, my informants, whose opinions carry much weight with me, have not always been pleased to read my accounts of their work (discussed below).

In sum, researching a controversial topic is by no means easy. On many occasions, and despite my fascination with this topic, I have mentally kicked myself for choosing such a contested subject for my dissertation. I wrote the following after a particularly harrowing confrontation with an informant: "As we were talking and after I hung up, I was feeling a lot of things. First and foremost, wondering why I picked such a controversial topic that was sure to get me in trouble...Running through my mind as [the informant] was talking were thoughts like, move to Greece and have a love baby; join the Peace Corps; quit school and choose a saner path." Obviously, I did none of these things and instead chose to complete the dissertation. Yet having learned that theory and methods are politics by other means, I am left with some important lessons and with unresolved questions. Seriously engaging the world of fetal surgery and its inhabitants meant integrating my own politics into this research. It was not merely an issue of "problem choice" as Weber (1949) asserted. Recognizing that fetal surgery exists on a social fault line meant critically investigating some hitherto invisible phenomena, such as how fetal surgery impacts women. I thus approached this topic with a sort of critical, feminist, engaged skepticism, which only deepened as I became more involved with my informants.

"Studying Up": Conducting Qualitative Research Among Elites

In qualitative research, "studying up" has generally meant studying people with more power than the researcher. This type of fieldwork usually takes place in "elite" settings, such as laboratories, hospitals, and corporations rather than on the street or in institutions such as prisons and shelters. Unlike more traditional study populations in sociology such as disenfranchised groups, in elite research informants often have considerably more power than the sociologist studying them. In other words, they are often more highly placed than the researcher in social hierarchies organized by gender, race, class, income, decisionmaking capability, integration within

elite social networks, and so on. This hierarchical relationship has important implications for the nature of the research. It may affect everything from the feelings of the researcher to how we present ourselves in research sites to issues regarding access, with often unsettling consequences.

In my study, I routinely sought information from elite medical personnel, specifically well-educated, mostly white, mostly male doctors with high incomes. As a struggling female graduate student, I often felt like an outsider vis-à-vis those whom I was studying. For example, I wrote the following notes after attending an ad hoc meeting on fetal management:

> About two minutes later, Dr. Graham came into the room with Dr. Murphy. They acknowledged me with a small hello and then spent the next few minutes conferring among themselves...A number of other men entered the room, none of whom I knew. As Tracy hadn't returned and I was the only woman in the room, I was beginning to feel very conspicuous. The men (mostly white and older) darted quick glances in my direction periodically, as if trying to figure out who I was and what I was doing there...At about 1:15 p.m., the room was full with several people standing near the door. I was sure that somebody would look around, spot me, and order me to give up my seat for somebody who really belonged there.

There were many other occasions in which I felt out of place, or was made to feel out of place. When I was finally able to interview one fetal surgeon, after many cancellations and reschedulings due to his busy schedule, he spent the entire interview reading his mail while answering my questions. By the time the interview was over, and despite having learned some valuable information, I was fuming at having been so casually dismissed by this "important" person. I found myself

thinking, "Fine. He wants to read his goddamned mail during this interview, wait until he sees the critical perspective I'm taking on fetal surgery. I'll show him!" Not exactly mature, reasonable thoughts, but emotions are an integral part of fieldwork and shape our research in surprising ways (Kleinman 1991). These experiences are further politicized in the retelling of them, because they seem to give weight to critics' claims that qualitative research *is* biased.

Feeling out of place in the field affected me in other ways, as well. For example, as a graduate student accustomed to wearing casual clothes, I quickly discovered that my appearance was both a liability and an advantage. When I was interviewing people and wanted to engage in impression management (Goffman 1959), I dressed up. Consider these notes:

> Since we were to be discussing logistics, I wanted to project a professional image for our meeting...I dressed in a forest green cotton dress, with black tights and low black shoes. Not too dressy, but definitely more "adult" than jeans and a turtleneck. Besides, every time I see Tracy she's wearing a dress or skirt and I wanted to fit in.

Yet I also discovered that my usual student uniform allowed me to blend in on many occasions. I looked just like any other non-threatening, powerless young graduate student, a persona greatly enhanced by being both female and blonde. In the sub-sterile room next to the OR during surgery, I was often mistaken for a medical student. This is not surprising, as Hilltop Hospital's halls are crawling with them. Although I was wearing scrubs, my student uniform--jeans and tennis shoes--was unmistakable under my gown. My graduate student persona also facilitated rapport with many of my non-surgeon informants, particularly social workers (all women) and young residents and postdoctoral fellows. The latter group, all male, also seemed to

respond to my gender in interesting ways, often volunteering information in a sort of flirtatious, boastful fashion.

Another issue in studying up, especially in medical and technoscientific settings, is the elite nature of specialized knowledge. Not only was I different from my informants in terms of gender, age, and class, but as a sociologist with no formal clinical training I often struggled to understand medical and scientific terms and practices. Yet this, too, turned out to be an advantage in certain ways. Not afraid to ask my informants what a specific term meant, I was often treated to elaborate answers peppered with useful data. Some informants assumed a pedagogical role in relation to me, the uninformed (young!) sociologist in their midst. Studying "up," in this case, meant that my informants could talk "down." Although I immersed myself in their world, they had very little understanding of my world or of what medical sociology or science studies are despite my best efforts to educate them. If I fully explained what I was doing, including my theoretical approach and methods, their eyes started to glaze over. If I abbreviated my project as "looking at social and ethical issues related to fetal surgery," both the project and I became more manageable in their eyes.

This somewhat schizophrenic "insider/outsider" (Collins 1986) position ultimately affected my access to the research site. Gaining access to the site had initially been easy, despite attempts to keep fetal surgery relatively secret in the early 1980s. A year or two prior to my seeking access, journalist Gina Kolata (1990) had researched and published a book about fetal surgery, undoubtedly paving the way for later incursions into the world of fetal surgery by other "outsiders." Yet Hilltop Hospital is also a teaching hospital; its practitioners are accustomed to the ubiquitous presence of students. The fact that I was a sociology student and not a medical student seemed to make very little difference. Once having gained access, maintaining it was also fairly easy. I routinely met with my key informants to discuss

logistics and update them on my progress. I blended in where appropriate and managed impressions as much as possible. Despite my best efforts to keep my informants' abreast of my project, I think fundamentally they assumed my work was like Kolata's: sort of congratulatory, awe-struck, and devoid of critical perspective. They were even enthusiastic about it, with Dr. Graham exclaiming during one interview, "What a great project! That's so cool." When they discovered that the nice, non-threatening young woman who had been studying them for three years was actually writing some not-so-nice things, a rather troubling scenario unfolded.

Throughout the duration of my research, I had routinely promised my informants that I would provide them with a copy of my dissertation when it was completed. I wanted their feedback through respondent validation, yet I also wanted them to have the entire argument in front of them when they evaluated it. I was quite nervous about showing them any of my work and worried about what effect(s) it would have on my relationship(s) with them. Had they wanted to, they could have read my published work at any time which was listed in the on-line database to which they have access. After visiting and interviewing a former patient of Hilltop Hospital, at her request I sent her several of my papers, including an unpublished version of Chapter 5. Apparently she disapproved of my argument and forwarded the paper to the fetal surgeons. I would not have been aware of any of this until I tried to conduct more interviews, except that one of my informants called me in a very distressed state. She had been confronted by colleagues about some of her comments in Chapter 5; although her identity was camouflaged, she was recognizable to others in the program when they read the paper. When I got off the phone with her, my ears ringing, my first thought was, "Shit. What a mess."

The informant's concern was that I had failed to adequately mask her identity, putting her in a compromised position vis-à-vis others in the fetal surgery program. She also said the fetal surgeons were quite angry about the paper and felt both

misrepresented and betrayed by me. I agreed to meet with her to discuss some of her strongest objections to my work. Yet I also made it clear that I am not in service to fetal surgery or its practitioners and that any attempts on their part to influence what I write would be construed as an infringement of my academic freedom. Despite this show of bravura, prior to my meeting with the unhappy informant I struggled with my own emotions regarding this snafu. Had I misrepresented myself and my work? Had I, in effect, been a "stealth researcher," moving silently through the world of fetal surgery with some of my intentions and politics cloaked like a Klingon bird of prey?[2] As I wrote in my fieldnotes, "I haven't misrepresented myself, but I also haven't always put my critical approach front and center. I have never lied to any of my informants, I have only chosen to withhold certain information that would likely compromise my project." And of course I had approval from the Committee on Human Research and had carefully sought and obtained thoroughly informed consent. Where were the methodological/ethical boundaries to be drawn?

My meeting with the informant was successful in that we discussed our differences and she felt that I listened to and, more importantly, heard her concerns. I agreed to remove some of the most obvious indicators of her identity from the paper, while also firmly sticking to my overall argument. For the most part, this informant agreed with my critical perspective and theoretical arguments. Yet she felt that I portrayed the fetal surgeons as having no integrity when they are in fact "really very nice people." I explained that, as a sociologist, I am not concerned with the

---

[2]My good friend and colleague Stefan Timmermans and I jointly came up with the term *stealth researcher* to describe how the nature of our work in elite settings makes us feel sometimes. Although we consider ourselves to be honest and ethical researchers, carefully following human subjects protocols and other ethical guidelines, in certain settings we foreground some identities and background others. In elite, controversial settings, it simply does not feel safe to put our politics "out there" for everybody to see. The "stealth" aspect of this research, then, refers to protecting certain aspects of our identities as researchers. It does not mean that we mask our empirical intentions, trick our informants, or engage in secret surveillance. Stealth research, as we define it, is not the "tearoom trade" (Humphreys 1970) revisited. There may be a better word than *stealth* to describe what we mean, but we have not found it yet. Timmermans and I intend to write a paper together exploring some of the methodological issues I am raising here. The Klingon reference is from *Star Trek*.

personalities of the fetal surgeons. Of course, much to my initial surprise, I found that I did like and respect the fetal surgeons who seemed to care very deeply about the work of "saving" babies. Yet whether or not they have integrity is *not* the sociological issue of relevance, although biographical information may make for juicier narrative. Rather, I care about these informants *as medical workers* within an experimental clinical specialty unfolding in a specific setting. Their work activities are more important to me than their personalities are. After meeting with the informant, I felt as if she and I were square with each other and had at least partially resolved the problems. That left the fetal surgeons--and my continued access--to negotiate.

The informant had told me that I was persona non grata in the Fetal Treatment Unit and that she would not be surprised if nobody ever wanted to talk to me again. She called me a few days after our meeting to "forewarn" me that things were "heating up" around my controversial paper. I was the subject of an oversight committee meeting and questions were being raised about the integrity of my research. Apparently, none of my informants remembered signing consent forms or agreeing to be audiotaped.[3] Essentially, the informant told me that surgeons seemed most upset about the possibility that they could be identified and the discomfort they may have felt about "having their words tossed back at them in this context." She offered to let them know that I had agreed to "tone down" the paper, but she would not agree to act as a mediator between me and the fetal surgeons. Because I desperately wanted to maintain my access to this research site, particularly to interview pregnant women, and because I was dismayed that people who had trusted me now felt betrayed, I opted for a somewhat conciliatory approach. Yet I also felt strongly that I had done

---

[3]All informants signed consent forms and specified whether their interviews would be taped or not. The Committee on Human Research at UCSF would not have allowed my work to proceed each year without these ethical safeguards in place. In addition, while some informants chose to remain anonymous in my written work, none of the fetal surgeons selected this option. For them, consent and anonymity did not become issues until they actually read my work.

nothing wrong, except perhaps exhibit poor judgment in sending an unpublished paper to an informant.

I wrote a letter to the director of the fetal surgery program, who had initially seemed very enthusiastic about my project. I reminded him that in numerous articles, he had called for ethical and social analysis of fetal surgery. I apologized for not being the one to give him the paper and explained how it had come into the hands of the former patient who mailed it to him. I outlined how I would fix the paper to more adequately mask the identities of my informants. I assertively explained what medical sociology is and offered to meet with him to discuss it further. Last, I informed him that my work had been well-received and I had already been approached by publishers about turning my dissertation into a book. Having presented publication of my work as inevitable, I suggested to him that his cooperation would ensure that I represent his program in the most accurate light. I asked him to call me to set up a meeting. Much to my dismay, I have had no contact with my informants since that time, and have been unable to secure continued access to my research site. I do, indeed, seem to be persona non grata. This disturbs me for a number of reasons, not least of which is my own creeping sensation of betrayal after having been so warmly welcomed into my fieldsite.

What this tale demonstrates, for me, is the power that some informants have in restricting access. I was unable to obtain enough data about the experiences of pregnant women to write Chapter 6 the way I had originally envisioned it. Not only has my access to pregnant women been barred by the surgeons, but I was warned by the aforementioned informant that "these guys play hardball." She told me to "be careful" and assure that my future as a researcher in/of medical worlds is not jeopardized. The perils of studying up, if they had not already been obvious to me, definitely became crystal clear at this point. My response to all of this was to temporarily set aside the access problem and write the dissertation, sans the data on

pregnant women that I had wanted to include. I have not recontacted my (former) informants since these events occurred, but still fully intend to send them my completed dissertation. What I realize now is that even though I have often felt powerless in my research site, for the reasons detailed above, as a researcher I hold a certain amount of power in being able to represent my informants' work and experiences. That I was not just a non-threatening, friendly graduate student in their midst came as something of a shock to all of us. I became sensitized to my own authority as a researcher, and my informants had to realign their perceptions of me in light of my written work.

In the end, I am uncomfortably left with many unresolved methodological dilemmas: When studying up, how should we represent ourselves in the field? Should we be forthright or are we better off withholding certain types of information or certain aspects of our political identities from our informants? How should we treat differences between the researcher and her informants? What should our relationship(s) with informants be? How can we best take advantage of our insider/outsider status while preserving the integrity of our informants? What are the rules regarding sharing our work with informants? Last, how do "studying up" and studying controversial topics shape our accountability in the field?

Whose Side Am I On?: Accountability in the Field

Although studying up posed significant methodological problems for me, I interviewed a wide range of informants, not all of whom had as much power and authority as the surgeons. As discussed in Chapter 5, fetal surgery is a diverse enterprise comprised of many different types of participants. Stacey (1984) has pointed out that medical work is organized hierarchically with surgeons and physicians at the top and other health care workers at the bottom. I also interviewed patients and their families as well as other "outsiders" such as political activists. Confronted

with this dissimilar field of informants, I needed to answer some key questions before I could proceed: Over whose shoulder(s) did I want to look? To whom were my political and intellectual allegiances? Who were my intended audiences? Why did I want to do this work? What did I hope to gain? Whose interests would it serve? Whose might it threaten? Becker (1977:123) argued that "the question is not whether we should take sides, since we inevitably will, but rather whose side we are on." Choosing a research methodology was about figuring out whose side I wanted to be on.[4]

My intention was to be accountable to all of my informants, but I found myself practicing accountability in different ways. I feel an acute responsibility to my informants to represent their experiences and work as accurately as possible, while also striving to maintain their anonymity and integrity. I would term this *methodological* accountability. That I may not have succeeded in achieving this, as evidenced by my now ambiguous status regarding access, fills me with tremendous anxiety and guilt. I also feel *politically* accountable to certain people in this domain, especially those implicated by experimental fetal surgery who I did not interview such as pregnant women. Yet because methodology and politics are often indistinguishable in practice, I am left with contradictions among all of the ways I am accountable to my informants.

As mentioned above, I began this research out of a deep commitment to women's health issues and a progressive reproductive rights philosophy. With respect to experimental fetal surgery, where others saw a life-saving heroic surgical procedure, I saw a pernicious threat to the health and autonomy of the pregnant women patients as well as to all women living in a context of contested and increasingly restricted access to reproductive rights. Thus, from the beginning, my

---

[4]I have explored these issues elsewhere (Casper 1994), focusing in particular upon our accountability to both humans and non-humans in our research.

allegiance has been to a sort of monolithic category of implicated actors called "women." Unfortunately, limited access to my research site toward the end of this project meant that I could not talk to many women patients, thus sending me creatively scavenging for data in other places.[5] Because I talked to so few women patients, I proceeded with my research in a persistent state of discomfort that I had not actually spoken *with* many of those whom I had decided to speak *for* in this dissertation. It was as if I had decided who the implicated actors were and had appointed myself as keeper of the data confirming this phenomena, yet had done so without actually speaking *with* the women. Clearly, this was a political and methodological conundrum in the making. But this was far from the end of the process.

As my research unfolded, I found my "loyalties" tested in interesting ways. While fetal surgery continued to affront my sense of what constitutes a good women's health practice, many of the pregnant women seeking fetal surgery were doing so enthusiastically. These women, desperate to "save" their ill-fated babies, were risking their own health and mortality to undergo this highly experimental procedure. Further, it was becoming clear to me through interviews with medical workers that many of the women choosing fetal surgery were opposed to abortion, for whatever reasons. Where a pro-choice woman might opt to abort a deformed fetus, as I myself might, these women were bypassing abortion in favor of medical intervention. How should I make sense of this within my own political framework? Clearly, I did not think that I "knew better" than these women. Nor, however, did I want to abandon a critical perspective which allowed for an analysis of the very real women's health dimensions of fetal surgery.

Without information about the diversity of pregnant women's experiences, I was confronted with the limitations of my analytical "straw woman." She was

---

[5]Videotapes featuring patients in fetal surgery programs, newspaper and magazine articles, television specials about fetal surgery, second-hand accounts from key informants--all provided data about the experiences of pregnant women.

beginning to seem like a chimera, a feature of my political imagination. How could I simultaneously maintain a critical feminist perspective and acknowledge that some women might actively choose fetal surgery? Ultimately, I developed the theoretical and political analysis which appears in Chapter 6 which assumes heterogeneous "straw women." Namely, I sought to reframe fetal surgery as a women's health issue, leaving room for the likely wide range of different women's experiences within this practice. I attempted to describe how pregnant women are not only *engaged* actors in fetal surgery who do a considerable amount of work, but they are also *implicated* actors in significant ways. Much to my relief, my "straw women" were not chimeras after all. Rather, they were products of the medical practices I was describing in my research; they were, in short, technomoms. I find that I am now accountable to these cyborg political figures (Casper 1995) as well as to the real women whose lives intersected with fetal surgery in profound ways.

Rather than attempting to fully describe how I sorted all of this out, a brief vignette from my research may provide some insight into how my sense of "feminist" accountability was challenged in the field. One of my informants was Susan Johnson, a former patient of the fetal surgery program at Hilltop Hospital whose little girl had been operated on prenatally and was now a few years old (see Chapter 6). I met with Susan and her husband, Jim, to discuss their experiences with fetal surgery. I had spoken with Jim by telephone several weeks earlier, and had learned then that he and Susan were very active in "pro-life" politics and were hoping to start a foundation to support the work of fetal surgery. I was eager to interview this couple, but also quite nervous about whether, and how severely, our different political beliefs would clash. I had been warned by informants at Hilltop Hospital that the Johnsons were "extreme" in their views, and I had also watched a television news program which featured their story. Thus, I approached the interview with some trepidation, which turned out to be

not wholly unfounded. My meeting with the Johnsons, as well as subsequent events, embodied many of the contradictions I have described.

I interviewed Susan and Jim in their natural setting, a fairly large city in the South. Accompanied by their three children, they picked me up at my hotel and took me to dinner at a nice Italian restaurant. Throughout the ride to dinner and the meal itself, Susan and Jim kept up a constant stream of conversation about their experiences with fetal surgery. They were incredibly enthusiastic and referred several times to their daughter, Elizabeth Ann, as "a miracle baby." I did very little work as an interviewer, preferring instead to let them say as much as they wanted. As they talked, it became clear that their enthusiasm for fetal surgery was grounded in more than just their satisfaction at having had a successful surgery. Their commitment to the making of the "unborn patient" was seemingly inextricably bound up with their anti-abortion politics.[6] Further, it was apparent from their discussion that their views were part of a religious right conservative political philosophy. Not only were they anti-choice, but their views were also anti-government, anti-gun control, anti-feminist, racist, and anti-homosexual.

After dinner, we went to their house to talk some more and to pick up some materials they had offered to give me. Only at this point in the evening did Susan and Jim ask me what my political position was, and I found myself unable to be completely forthcoming. I told them that because the subject was controversial, I had decided early on not to discuss my politics with my informants. Although they accepted this explanation, my consternation increased when Susan told me she felt like I had agreed with many of her comments during dinner. Egads, I thought, and quickly turned the focus of conversation back to Susan and Jim. As they continued to tell me about fetal surgery and anti-abortion politics, I found myself becoming increasingly uncomfortable.

---

[6]They preferred this terminology to the word "fetus," but did not seem to grasp the irony of my dissertation title.

While continuing to listen, smile, and converse, my insides were churning with emotion. I felt affronted by their extreme views, sympathetic to their concern with their daughter's well-being, honored that they had welcomed me into their home, and guilty because I could not wait to get back to my hotel. Contradictions abounded.

The evening eventually came to a close, with me sighing in relief and promising to send them some of my papers. A few days later, on my way back to San Francisco and away from the lions' den, I began to wonder whether I should have just told them that I was a pro-choice feminist. What was I so afraid of? In retrospect, I realized I did not feel "safe" in that setting; they held extreme views (the pro-gun stance in particular scared me) and I was also dependent on them for a ride back to my hotel in a strange city. Coming from San Francisco, perhaps the most progressive city in the U.S., I felt like the proverbial fish out of water. I did not think I was being paranoid, rather merely trying to avoid what could have been a tense situation. I also wanted to prevent *myself* from saying something inappropriate or critical to my informants, particularly when they were "educating" their oldest son about the evils of homosexuality.

Although I did not feel at all politically accountable to the Johnsons, I did feel methodologically accountable and wanted to reciprocate their hospitality in some way. I sent them a sincere letter disclosing my pro-choice position and included a few of my papers (two published, one unpublished). I thanked them for spending so much time with me and sharing their story, and I said that I deeply respected their commitment to a political stance even if I did not agree with their position. Because we had a nice rapport despite the profound differences bubbling beneath the surface of our encounter, I suggested that we speak again after they had a chance to read my work. Although we are located on opposite ends of the political spectrum, I felt that we could establish a dialogue and I also very much wanted to get their feedback on my analysis. This approach was more optimistic than naive. I was not surprised when I never heard

back from the Johnsons directly. But I did get feedback of a sort when Susan mailed my unpublished paper to my Hilltop Hospital informants, generating a cascade of access problems.

How was I to make sense of this situation and my own feelings about it? I had spent several hours with a bonafide (former) "pregnant woman patient," someone to whom I wanted to feel strong allegiance. Yet to my great chagrin, I did not feel such an allegiance and did not even like Susan Johnson very much. Although I found her experiences with fetal surgery fascinating and respected her commitment to her daughter's health, she was a prime example of how (some) women participate in their own medicalization. If anything, listening to Susan discuss her experiences at Hilltop Hospital only deepened my belief that fetal surgery is *not* a good practice in terms of women's health. Yet, Susan's world view was anathema to me and did not inspire political accountability on my part. Could I be methodologically accountable to Susan and speak on her behalf when I was so repelled by her politics? To complicate matters, I felt tremendous allegiance toward some of my informants at the hospital who were negatively affected when the Johnsons sent my unpublished paper. I was stung when one of my informants, a woman who I considered an ally, suggested that I needed to "reevaluate" my "feminist politics."

In retrospect, it seems to me that I was dealing with the implications of taking sides in research. Striving to be methodologically accountable to informants is hard work; layering political accountability on top of that only deepens the contradictions. In a research site inhabited by a disparate group of informants with different perspectives, it is not surprising that my accountability took shape in various ways. In terms of methodological nuts and bolts, I carefully selected rich and appropriate data sources; I chose analytical strategies which suited these sources; I attempted to represent my informants' experiences in the most accurate and sensitive manner possible. In short, I followed all the basic rules of qualitative research. In terms of

political accountability, however, there are no basic rules. Figuring out how to manage my commitments in the field required a great deal of effort. In the process, I discovered that choosing to acknowledge rather than attempt to "set aside" my engagement with the research is not without its costs. Ultimately I would argue that taking sides is worth the effort if our only alternative is to retreat into the hollow position of "objective" analyst which is too often dishonest. As Haraway (1991:187) has written, "feminists have to insist on a better account of the world."

Bibliography

Abbott, Andrew. 1988. *The System of Professions: An Essay on the Division of Expert Labor*. Chicago: University of Chicago Press.

Abir-Am, Pnina, and Dorinda Outram, ed. 1987. *Uneasy Careers and Intimate Lives: Women in Science 1789-1979*. New Brunswick: Rutgers University Press.

Abramovich, D.R., and K.R. Page. 1989. Fetal Control of Amniotic Fluid Volume in the Human. In *Fetal Physiology and Pathology*, edited by P. Belfort, J.A. Pinotti, and T.K.A.B. Eskes, 9-14. Carnforth: Parthenon Publishing Group.

Adams, Alice E. 1994. *Reproducing the Womb: Images of Childbirth in Science, Feminist Theory, and Literature*. Ithaca: Cornell University Press.

Adamsons, Karlis, Jr. 1966. Fetal Surgery. *New England Journal of Medicine*, 275:204-206.

Adamsons, Karliss, Jr., V.J. Freda, L.S. James, and M.E. Towell. 1965. Prenatal Treatment of Erythroblastosis Fetalis Following Hysterotomy. *Pediatrics*, 35:848-855.

Adzick, N. Scott. 1992. Fetal Animal and Wound Implant Models. In *Fetal Wound Healing*, edited by N. Scott Adzick, and Michael T. Longaker, 71-82. New York: Elsevier Science Publishing Co.

Adzick, N. Scott, and Michael R. Harrison. 1992. The Fetal Surgery Experience. In *Fetal Wound Healing*, edited by N. Scott Adzick, and Michael T. Longaker, 1-23. New York: Elsevier.

Adzick, N. Scott, and Michael T. Longaker. 1992a. Characteristics of Fetal Tissue Repair. In *Fetal Wound Healing*, edited by N. Scott Adzick, and Michael T. Longaker, 53-70. New York: Elsevier.

Adzick, N. Scott, and Michael T. Longaker. 1992b. Preface. In *Fetal Wound Healing*, edited by N. Scott Adzick, and Michael T. Longaker, xi. New York: Elsevier.

Annas, George J., and Sherman Elias. 1989. The Politics of Transplantation of Human Fetal Tissue. *New England Journal of Medicine*, 320:1079-1082.

Anonymous. 1963. Baby Makes Headlines Over World: Case a Tribute to Doctors. [Unknown newspaper.]

Anonymous. 1968. Fetology: The Smallest Patients. *Child and Family Quarterly*, 8(2).

Anonymous. 1972. *More Famous New Zealanders*. Christchurch: Whitcombe and Tombs Ltd.

Anspach, Renee R. 1993. *Deciding Who Lives: Fateful Choices in the Intensive-Care Nursery*. Berkeley: University of California Press.

Aronowitz, Stanley. 1988. *Science as Power: Discourse and Ideology in Modern Society*. Minneapolis: University of Minnesota Press.

Aronson, Naomi. 1984. Science as a Claims-Making Activity: Implications for Social Problems Research. In *Studies in the Sociology of Social Problems*, edited by Joseph Schneider, and John Kitsuse, 1-30. Norwood: Ablex Publishing Corp.

Asensio, Stanley H., Juan G. Figueroa-Longo, and Ivan A. Pelegrina. 1966. Intrauterine Exchange Transfusion. *American Journal of Obstetrics and Gynecology*, 95(8):1129-1133.

Associated Press. 1991. Experimental Maternal Blood Test for Fetal Ills. *New York Times*, October 9, B6.

Associated Press. 1994. Gap Seen in Infant Mortality. *New York Times*, May 3, B7.

Associated Press. 1995. Trial OK'd in Abortion Clinic Killings. *Sacramento Bee*, August 24,

Atwood, Margaret. 1985. *The Handmaid's Tale*. New York: Fawcett Crest.

Backman, Carl B. 1982. Institutional History. Unpublished paper based on doctoral dissertation research.

Balsamo, Ann. 1990. Rethinking Ethnography: A Work for the Feminist Imagination. *Studies in Symbolic Interaction*, 11:45-57.

Balsamo, Anne. 1992. On the Cutting Edge: Cosmetic Surgery and the Technological Production of the Gendered Body. *Camera Obscura*, 28:207-238.

Barron, S.L., and D.F. Roberts, ed. 1995. *Issues in Fetal Medicine: Proceedings of the Twenty-Ninth Annual Symposium of the Galton Institute, London, 1992.* New York: St. Martin's Press.

Becker, Howard S. 1977. *Sociological Work: Method and Substance*. New Brunswick, NJ: Transaction Books.

Becker, Howard S. 1982. *Art Worlds*. Berkeley: University of California Press.

Becker, Howard. 1986. *Doing Things Together*. Evanston: Northwestern University Press.

Bell, Susan E. 1987. Changing Ideas: The Medicalization of Menopause. *Social Science and Medicine*, 24(6):535-542.

Berg, Marc. 1992. The Construction of Medical Disposals: Medical Sociology and Medical Problem Solving in Clinical Practice. *Sociology of Health and Illness*, 14(2):151-180.

Berg, Marc. 1995. Rationalizing Medical Work: A Study of Decision Support Techniques and Medical Practices. Doctoral dissertation, Department of Health Ethics and Philosophy, University of Limburg.

Berger, Peter L., and Thomas Luckmann. 1966. *The Social Construction of Reality: A Treatise in the Sociology of Knowledge*. New York: Anchor Books.

Bevis, David C.A. 1952. The Antenatal Prediction of Hemolytic Disease. *Lancet*, 1:395.

Bevis, David C.V. 1956. Blood Pigments in Hemolytic Disease of the Newborn. *Journal of Obstetrics and Gynecology, British Empire*, 63:68.

Blumer, Herbert. 1969. *Symbolic Interactionism: Perspective and Method*. Englewood Cliffs, NJ: Prentice-Hall.

Bookstein, Robert. 1990. Research with Fetal Tissue. *Nature*, 344:284.

Borrell, Merriley. 1989. *Album of Science: The Biological Sciences in the Twentieth Century*. New York: Charles Scribner's Sons.

Boston Women's Health Book Collective. 1994. Informed Consent: Principle vs. Practice. *UCSF Women's Resource Center*, 8(27):7, 12.

Boyd, R.D.H., and C.P. Sibley. 1989. Potential for Control of Placental Transfer of Osmotically Important Small Molecules. In *Fetal Physiology and Pathology*, edited by P. Belfort, J.A. Pinotti, and T.K.A.B. Eskes, 3-8. Carnforth: Parthenon Publishing Group.

Brans, Yves W., and Thomas J. Kuehl, ed. 1988. *Nonhuman Primates in Perinatal Research.* New York: John Wiley and Sons.

Brieger, Gert H. 1980. History of Medicine. In *A Guide to the Culture of Science, Technology, and Medicine*, edited by Paul T. Durbin, 121-194. New York: Free Press.

Brieger, Gert H. 1980. Surgery. In *The Education of American Physicians: Historical Essays*, edited by Ronald L. Numbers, 175-204. Berkeley: University of California Press.

Brody, Jane E. 1995. New Procedure for Abortion. *Sacramento Bee*, August 31, A1, A20.

Brown, E. Richard. 1979. *Rockefeller Medicine Men: Medicine and Capitalism in America*. Berkeley: University of California Press.

Bucher, Rue. 1962. Pathology: A Study of Social Movements within a Profession. *Social Problems*, 10(1):40-51.

Bucher, Rue. 1988. On the Natural History of Health Care Occupations. *Work and Occupations*, 15(2):131-147.

Bucher, Rue, and Anselm Strauss. 1961. Professions in Process. *American Journal of Sociology*, 66:325-334. [Reprinted in Anselm L. Strauss, 1991. *Creating Sociological Awareness*. New Brunswick, NJ: Transaction, 245-262.

Burd, D. Andrew R., Michael T. Longaker, and N. Scott Adzick. 1992. In Vitro Fetal Wound Healing Models. In *Fetal Wound Healing*, edited by N. Scott Adzick, and Michael T. Longaker, 255-264. New York: Elsevier.

Burrage, Michael. 1990. Introduction: The Professions in Sociology and History. In *Professions in Theory and History: Rethinking the Study of the Professions*, edited by M. Burrage, and R. Torstendahl, 1-23. London: Sage Publications.

Busch, Lawrence. 1991. Manufacturing Plants: Notes on the Culture of Nature and the Nature of Culture. *International Journal of Sociology of Agriculture and Food*, 1:105-115.

Cadoff, Jennifer. 1994. Miracle Babies: Fetal Surgery's Lifesaving Results. *Parents*, 53-55.

Callon, Michel. 1985. Some Elements of a Sociology of Translation: Domestication of the Scallops and the Fishermen of St. Brieuc Bay. In *Power, Action, Belief: A New Sociology of Knowledge?*, edited by John Law, 196-233. London: Routledge and Kegan Paul.

Cambrosio, Alberto, and Peter Keating. 1988. 'Going Monoclonal': Art, Science, and Magic in the Day-to-Day Use of Hybridoma Technology. *Social Problems*, 35(3):244-260.

Casper, Monica J. 1992. Anatomy of a Scientific Controversy: The Politics of Fetal Tissue Research. Unpublished paper, Department of Social and Behavioral Sciences, University of California, San Francisco.

Casper, Monica J. 1993. Deconstructing the Fetus: Toward a Sociology of Fetal Practices in Science and Medicine. Unpublished qualifying examination, Department of Social and Behavioral Sciences, University of California, San Francisco.

Casper, Monica J. 1994. At the Margins of Humanity: Fetal Positions in Science and Medicine. *Science, Technology, and Human Values*, 19(3):307-323.

Casper, Monica J. 1994. Reframing and Grounding 'Non-Human' Agency: What Makes a Fetus an Agent? *American Behavioral Scientist*, 37(6).

Casper, Monica J. 1995. Fetal Cyborgs and Technomoms on the Reproductive Frontier: Or, Which Way to the Carnival? In *The Cyborg Handbook*, edited by Chris Hables Gray, Heidi J. Figueroa-Sarriera, and Steven Mentor, New York: Routledge.

Casper, Monica J., and Marc Berg. 1995. Constructivist Perspectives on Medical Work: Medical Practices and Science and Technology Studies. *Science, Technology, and Human Values*, 20(4).

Casper, Monica J., and Lisa Jean Moore. 1995. Inscribing Bodies, Inscribing the Future: Sex and Reproduction in Outer Space. *Sociological Perspectives*, 38(5).

Chervenak, Frank A., and Laurence B. McCullough. 1985. Perinatal Ethics: A Practical Method of Analysis of Obligations to Mother and Fetus. *Obstetrics and Gynecology*, 66(3):442-446.

Clarke, Adele E. 1984. Subtle Forms of Sterilization Abuse: A Reproductive Rights Analysis. In *Test-Tube Women: What Future For Motherhood?*, edited by Rita Arditti, Renate Duelli Klein, and Shelley Minden, 188-212. London: Pandora Press.

Clarke, Adele E. 1986. Qualitative Research in the Historical Sociology of Science: Issues and Challenges. Presented at meetings of the Pacific Sociological Association, Denver, CO.

Clarke, Adele E. 1987. Research Materials and Reproductive Science in the United States, 1910-1940. In *Physiology in the American Context, 1845-1940*, edited by Gerald L. Geison, 323-350. Bethesda: American Physiological Society.

Clarke, Adele E. 1990. Controversy and the Development of Reproductive Sciences. *Social Problems*, 37(1):18-37.

Clarke, Adele E. 1991. Social Worlds/Arenas Theory as Organizational Theory. In *Social Organization and Social Process: Essays in Honor of Anselm Strauss*, edited by David R. Maines, 119-158. New York: Aldine de Gruyter.

Clarke, Adele E. 1996. *Disciplining Reproduction: Modernity, American Life Sciences, and 'The Problem of Sex'*. Berkeley: University of California Press, forthcoming.

Clarke, Adele E. 1996b. Who Claims Humans as Research Materials? On the Problematics of Subjects Who Speak. In *Humans as Research Materials*, edited by Gerald L. Geison, Princeton: Princeton University Press, forthcoming.

Clarke, Adele E., and Joan H. Fujimura, ed. 1992a. *The Right Tools for the Job: At Work in Twentieth-Century Life Sciences.* Princeton: Princeton University Press.

Clarke, Adele E., and Joan H. Fujimura. 1992b. What Tools? Which Jobs? Why Right? In *The Right Tools for the Job: At Work in Twentieth-Century Life Sciences,* edited by Adele E. Clarke, and Joan H. Fujimura, 3-44. Princeton: Princeton University Press.

Clarke, Adele E., and Theresa Montini. 1993. The Many Faces of RU486: Tales of Situated Knowledges and Technological Contestations. *Science, Technology, and Human Values*, 18(1):42-78.

Collins, H.M., and Steven Yearley. 1992. Journey Into Space. In *Science as Practice and Culture,* edited by Andrew Pickering, 369-389. Chicago: University of Chicago Press.

Collins, Patricia Hill. 1986. Learning from the Outsider Within: The Sociological Significance of Black Feminist Thought. *Social Problems*, 33(6).

Council on Scientific Affairs, and Council on Ethical and Judicial Affairs. 1990. Medical Applications of Fetal Tissue Transplantation. *Journal of the American Medical Association*, 263(4):565-570.

Creasy, Robert K., and Robert Resnick, ed. 1994. *Maternal-Fetal Medicine: Principles and Practice.* Philadelphia: W.B. Saunders.

Crombleholme, Timothy M., Esmail D. Zanjani, Jacob C. Langer, and Michael R. Harrison. 1991. Transplantation of Fetal Cells. In *The Unborn Patient: Prenatal Diagnosis and Treatment,* edited by Michael R. Harrison, Mitchell S. Golbus, and Roy A. Filly, 495-507. Philadelphia: W.B. Saunders Company.

Daffos, Fernand. 1991. Fetal Blood Sampling. In *The Unborn Patient: Prenatal Diagnosis and Treatment,* edited by Michael R. Harrison, Mitchell S. Golbus, and Roy A. Filly, 75-81. Philadelphia: W.B. Saunders Company.

Dancis, Joseph. 1987. Placental Physiology. In *Prenatal and Perinatal Biology and Medicine,* edited by Norman Kretchmer, Edward J. Quilligan, and John D. Johnson, 1-34. Chur: Harwood Academic Publishers.

Daniels, Arlene Kaplan. 1987. Invisible Work. *Social Problems*, 34(5):403-415.

Daniels, Cynthia R. 1993. *At Women's Expense: State Power and the Politics of Fetal Rights*. Cambridge: Harvard University Press.

Dawes, Geoffrey S. 1989. Mont Liggins on Birth, the Fetal Lung and the Weddell Seal. In *Advances in Fetal Physiology: Reviews in Honor of G.C. Liggins,* edited by Peter D. Gluckman, Barbara M. Johnston, and Peter W. Nathanielsz, 1-12. Ithaca: Perinatology Press.

Day, Beth, and Margaret Liley. 1968. *The Secret World of the Baby.* New York: Random House.

Denzin, Norman K. 1992. *Symbolic Interactionism and Cultural Studies: The Politics of Interpretation.* Oxford: Blackwell.

Denzin, Norman, and Yvonna Lincoln, ed. 1994. *Handbook of Qualitative Research.* Newbury Park: Sage.

Denzin, Norman. 1989. *Interpretive Interactionism.* Newbury Park, CA: Sage.

Didion, Joan. 1968. *Slouching Towards Bethelem.* New York: Simon and Schuster.

Donovan, Patricia. 1990. Funding Restrictions on Fetal Research: The Implications for Science and Health. *Family Planning Perspectives*, 22(5):224-231.

Downey, Gary Lee, Joseph Dumit, and Sarah Williams. 1992. Granting Membership to the Cyborg Image. Paper presented at meetings of the American Anthropological Association, San Francisco, CA.

Downey, Gary, Joseph Dumit, and Sharon Traweek, ed. 1995. *Cyborgs and Citadels: Anthropological Interventions on the Borderlands of Technoscience.* Seattle: University of Washington Press, forthcoming.

Duden, Barbara. 1993. *Disembodying Women: Perspectives on Pregnancy and the Unborn.* Cambridge: Harvard University Press.

Editor. 1989. Fetal Tissue Wrangle. *Nature*, 342:104.

Edmonds, Larry D. 1990. Temporal Trends in the Prevalence of Congenital Malformations at Birth Based on the Birth Defects Monitoring Program, U.S., 1979-87. *Morbidity and Mortality Weekly Report, CDC Surveillance Summaries*, 39(SS-4).

Epstein, Steve. 1995. The Critique of Pure Science: AIDS Activism and the Struggle for Credibility in the Reform of Clinical Trials. *Science, Technology, and Human Values*, 20(4).

Erikson, Kai. 1990. Introduction. In *The Nature of Work: Sociological Perspectives,* edited by Kai Erikson, and Steven Peter Vallas, 1-15. New Haven: Yale University Press.

Fielding, Nigel G., and Jane L. Fielding. 1986. *Linking Data.* Beverly Hills: Sage.

Finger, Anne. 1984. Claiming *All* of Our Bodies: Reproductive Rights and Disability. In *Test-Tube Women: What Future for Motherhood?,* edited by Rita Arditti, Renate Duelli Klein, and Shelley Minden, 281-297. London: Pandora Press.

Fisher, Sue. 1988. *In the Patient's Best Interests: Women and the Politics of Medical Decisions.* New Brunswick: Rutgers University Press.

Fishman, Pamela. 1978. Interaction: The Work Women Do. *Social Problems*, 25(4):397-406.

Flake, Alan W., Michael R. Harrison, and N. Scott Adzick. 1988. Intrauterine Intervention: Fetal Surgery in the Nonhuman Primate. In *Nonhuman Primates in Perinatal Research,* edited by Yves W. Brans, and Thomas J. Kuehl, 245-262. New York: John Wiley and Sons.

Fletcher, John C. 1990. Controversies in Research Ethics Affecting the Future of Human Gene Therapy. *Human Gene Therapy*, 1:307-324.

Fletcher, John C. 1991. The Suppression of Biomedical Science in the U.S. In *The Politics of Abortion: The Impact on Scientific Research,* edited by National Abortion Rights Action League Foundation, 9-10. Washington, DC: Bass and Howes, Inc.

Fletcher, John C., and Albert R. Jonsen. 1991. Ethical Considerations in Fetal Treatment. In *The Unborn Patient: Prenatal Diagnosis and Treatment,* edited by Michael R. Harrison, Mitchell S. Golbus, and Roy A. Filly, 14-18. Philadelphia: W.B. Saunders Company.

Fonow, Mary Margaret, and Judith A. Cook, ed. 1991. *Beyond Methodology: Feminist Scholarship as Lived Research.* Bloomington: University of Indiana Press.

Foucault, Michel. 1973. *The Birth of the Clinic: An Archaeology of Medical Perception.* New York: Vintage Books.

Fowden, A.L. 1989. The Endocrine Regulation of Fetal Metabolism and Growth. In *Advances in Fetal Physiology: Reviews in Honor of G.C. Liggins,* edited by Peter D. Gluckman, Barbara M. Johnston, and Peter W. Nathanielsz, 229-244. Ithaca: Perinatology Press.

Franklin, Sarah. 1991. Fetal Fascinations: New Dimensions to the Medical-Scientific Construction of Personhood. In *Off-Centre: Feminism and Cultural Studies,* edited by Sarah Franklin, Celia Lury, and Jackie Stacey, 190-205. London: Harper Collins.

Freda, V.J., and K. Adamsons Jr. 1964. Exchange Transfusion In Utero: Report of a Case. *American Journal of Obstetrics and Gynecology,* 89:817-821.

Freidson, Eliot. 1986. *Professional Powers: A Study of the Institutionalization of Formal Knowledge.* Chicago: University of Chicago Press.

Freidson, Eliot. 1994. *Professionalism Reborn: Theory, Prophecy, and Policy.* Chicago: University of Chicago Press.

Frey, Darcy. 1995. Does Anyone Here Think This Baby Can Live? *New York Times Magazine,* 22-31, 36, 44, 47.

Fujimura, Joan H. 1987. Constructing 'Do-Able' Problems in Cancer Research: Articulating Alignment. *Social Studies of Science,* 17:257-293.

Fujimura, Joan H. 1988. The Molecular Biological Bandwagon in Cancer Research: Where Social Worlds Meet. *Social Problems,* 35(3):261-283.

Fujimura, Joan H. 1992. Crafting Science: Standardized Packages, Boundary Objects, and 'Translation'. In *Science as Practice and Culture,* edited by Andrew Pickering, 168-214. Chicago: University of Chicago Press.

Fung, Christopher H.K., and James W. Lo. 1990. Alternatives to Using Fetal Tissue from Induced Abortions. *Journal of the American Medical Association,* 264(1):34.

Galison, Peter. 1987. *How Experiments End.* Chicago: University of Chicago Press.

Garber, M. 1989. Spare Parts: The Surgical Construction of Gender. *Differences,* 1:137-159.

Geison, Gerald L. 1979. Divided We Stand: Physiologists and Clinicians in the American Context. In *The Therapeutic Revolution: Essays in the Social History of American Medicine,* edited by Morris J. Vogel, and Charles Rosenberg, 67-90. Philadelphia: University of Pennsylvania Press.

Geison, Gerald L., ed. 1987. *Physiology in the American Context: 1850-1940.* Bethesda: American Physiological Society.

Gershon, Diane. 1990a. Move to Overturn Ban. *Nature,* 346:598.

Gershon, Diane. 1990b. Will Ban Provoke Challenge? *Nature,* 347:4.

Gershon, Diane. 1991. New Panel for Ethical Issues. *Nature,* 349:184.

Gilbert, Scott F., ed. 1991. *A Conceptual History of Modern Embryology.* New York: Plenum.

Gilbert, Susan. 1993. Waiting Game. *New York Times Magazine*, 70-73.

Gilman, Sander. 1986. Black Bodies, White Bodies: Toward an Iconography of Female Sexuality in Late 19th-Century Art, Medicine and Literature. *Critical Inquiry*, 12:204-242.

Ginsburg, Faye D., and Rayna Rapp, ed. 1995. *Conceiving the New World Order: The Global Politics of Reproduction.* Berkeley: University of California Press.

Glaser, Barney G., and Anselm Strauss. 1967. *The Discovery of Grounded Theory.* Chicago: Aldine.

Gluckman, Peter D., Barbara M. Johnston, and Peter W. Nathanielsz, ed. 1989. *Advances in Fetal Physiology: Reviews in Honor of G.C. Liggins.* Ithaca: Perinatology Press.

Goffman, Erving. 1959. *The Presentation of Self in Everyday Life.* Garden City, NY: Doubleday Anchor Books.

Golbus, Mitchell. 1993. Fetal Therapy. Presented at Institute of Medicine Conference on Fetal Research and Applications, Irvine, CA, June 20-22.

Gold, Rachel Benson, and Cory L. Richards. 1994. Securing American Women's Reproductive Health. In *The American Woman 1994-95: Where We Stand [Women and Health],* edited by Cynthia Costello, and Anne J. Stone, 197-222. New York: W.W. Norton and Company.

Gold, Rachel Benson, and Dorothy Lehrman. 1989. Fetal Research Under Fire: The Influence of Abortion Politics. *Family Planning Perspectives*, 21(1):6-11.

Gooding, David, Trevor Pinch, and Simon Schaffer, ed. 1989. *The Uses of Experiment: Studies in the Natural Sciences.* New York: Cambridge University Press.

Greely, Henry T., Thomas Hamm, Rodney Johnson, Carole R. Price, Randy Weingarten, and Thomas Raffin. 1989. The Ethical Use of Human Fetal Tissue in Medicine. *New England Journal of Medicine*, 320(16):1093-1096.

Green, G.H. 1985. Historic Perspective on Liley's 'Fetal Transfusion'. *Vox Sanguinis*, 48:184-187.

Green, G.H. 1986. William Liley and Fetal Transfusion: A Perspective in Fetal Medicine. *Fetal Therapy*, 1:18-22.

Green, G.H., A.W. Liley, and G.C. Liggins. 1964. The Place of Foetal Transfusion in Haemolytic Disease. Paper presented at the 7th Australian Congress in Obstetrics and Gynaecology, September 21-25, Surfers Paradise, Queensland.

Greenwood, Ernest. 1957. Attributes of a Profession. *Social Work*, July:45-55.

Grobstein, Clifford. 1988. *Science and the Unborn: Choosing Human Futures.* New York: Basic Books, Inc.

Hall, Peter M. 1987. Interactionism and the Study of Social Organization. *Sociological Quarterly*, 28(1):1-22.

Halpern, Sydney A. 1988. *American Pediatrics: The Social Dynamics of Professionalism, 1880-1980.* Berkeley: University of California Press.

Halpern, Sydney A. 1992. Dynamics of Professional Control: Internal Coalitions and Crossprofessional Boundaries. *American Journal of Sociology*, 97(4):994-1021.

Hana Biologics Inc. 1988. *Annual Report.* Hana Biologics Inc.

Hana Biologics Inc. 1989. *Annual Report.* Hana Biologics Inc.

Hana Biologics Inc. 1990. *Annual Report.* Hana Biologics Inc.

Haraway, Donna. 1989. *Primate Visions: Gender, Race, and Nature in the World of Modern Science.* New York: Routledge.

Haraway, Donna J. 1991. *Simians, Cyborgs, and Women: The Reinvention of Nature.* New York: Routledge.

Haraway, Donna. 1992. The Promises of Monsters: A Regenerative Politics for Inappropriate/d Others. In *Cultural Studies,* edited by Lawrence Grossberg, Cary Nelson, and Paula Treichler, 295-337. New York: Routledge.

Harding, Jane E., and Valerie Charlton. 1991. Experimental Nutritional Supplementation for Intrauterine Growth Retardation. In *The Unborn Patient: Prenatal Diagnosis and Treatment,* edited by Michael R. Harrison, Mitchell S. Golbus, and Roy A. Filly, 598-613. Philadelphia: W.B. Saunders Company.

Harding, Sandra. 1986. *The Science Question in Feminism.* Ithaca: Cornell University Press.

Harding, Sandra. 1989. Taking Responsibility for Our Own Gender, Race, Class: Transforming Science and the Social Studies of Science. *Rethinking Marxism,* 2(3):8-19.

Harding, Sandra. 1991. *Whose Science? Whose Knowledge? Thinking from Women's Lives.* Ithaca: Cornell University Press.

Harrison, Michael R. 1991. The Fetus as a Patient: Historical Perspective. In *The Unborn Patient: Prenatal Diagnosis and Treatment,* edited by Michael R. Harrison, Mitchell S. Golbus, and Roy A. Filly, 3-7. Philadelphia: W.B. Saunders Company.

Harrison, Michael R. 1991a. Professional Considerations in Fetal Treatment. In *The Unborn Patient: Prenatal Diagnosis and Treatment,* edited by Michael R. Harrison, Mitchell S. Golbus and Roy A. Filly, 8-13. Philadelphia: W.B. Saunders Company.

Harrison, Michael R. 1991b. Selection for Treatment: Which Defects are Correctable. In *The Unborn Patient: Prenatal Diagnosis and Treatment,* edited by Michael R. Harrison, Mitchell S. Golbus and Roy A. Filly, 159-165. Philadelphia: W.B. Saunders Company.

Harrison, Michael R., and N. Scott Adzick. 1991. The Fetus as a Patient: Surgical Considerations. *Annals of Surgery,* 213(4):279-291.

Harrison, Michael R., and Roy A. Filly. 1991. The Fetus with Obstructive Uropathy: Pathophysiology, Natural History, Selection, and Treatment. In *The Unborn Patient: Prenatal Diagnosis and Treatment,* edited by Michael R. Harrison, Mitchell S. Golbus, and Roy A. Filly, 328-402. Philadelphia: W.B. Saunders.

Harrison, Michael R., and Michael T. Longaker. 1991. Maternal Risk and the Development of Fetal Surgery. In *The Unborn Patient: Prenatal Diagnosis and Treatment,* edited by Michael R. Harrison, Mitchell S. Golbus, and Roy A. Filly, 189-202. Philadelphia: W.B. Saunders Company.

Harrison, Michael R., N. Scott Adzick, and Alan W. Flake. 1993. Congenital Diaphragmatic Hernia: An Unsolved Problem. *Seminars in Pediatric Surgery,* 2(2):109-112.

Harrison, Michael R., Mitchell S. Golbus, and Roy A. Filly, ed. 1991. *The Unborn Patient: Prenatal Diagnosis and Treatment.* Philadelphia: W.B. Saunders Company.

Hartouni, Valerie. 1991. Containing Women: Reproductive Discourse in the 1980s. In *Technoculture,* edited by Constance Penley, and Andrew Ross, 27-56. Minneapolis: University of Minnesota Press.

Healy, Bernadine. 1991. Testimony before House Energy and Commerce/Health Subcommittee. Hearings on NIH Reauthorization Bill (HR1532), Washington, DC.

Hess, David J. 1990. The Anthropology of Science and the New Ethnography. Presented at meetings of the Society for Social Studies of Science.

Hess, David J. 1992. Introduction: The New Ethnography and the Anthropology of Science and Technology. In *Knowledge and Society: The Anthropology of Science and Technology,* edited by David J. Hess, and Linda L. Layne, 1-26. Greenwich, CT: JAI Press.

Hess, David J., and Linda L. Layne, ed. 1992. *Knowledge and Society: The Anthropology of Science and Technology.* Greenwich, CT: JAI Press.

Hillebrecht, John M. 1989. Regulating the Clinical Uses of Fetal Tissue. *Journal of Legal Medicine*, 10(2):269-322.

Hilts, Philip J. 1991a. Anguish Over Medical First: Tissue from Fetus to Fetus. *New York Times*, April 16,

Hilts, Philip J. 1991b. Fetal Transplant Said to Block Defect. *New York Times*, November 21,

Hilts, Philip J. 1991c. Groups Set Up Panel on Use of Fetal Tissue. *New York Times*, January 8,

Hilts, Philip J. 1992. Fetal-Tissue Bank Not Viable Option, Agency Memo Says. *New York Times*, July 27, A1, A7.

Hilts, Philip J. 1994. Research Animals Used Less Often. *New York Times*, March 3, A7.

Hirschauer, Stefan. 1991. The Manufacture of Bodies in Surgery. *Social Studies of Science*, 21:279-319.

Hochschild, Arlie Russell. 1983. *The Managed Heart: Commercialization of Human Feeling*. Berkeley: University of California Press.

Hogle, Linda. 1993. Margins of Life; Boundaries of the Body. Paper presented at meetings of the American Association of Applied Anthropology, San Antonio, TX.

Howell, Lori J., N. Scott Adzick , and Michael R. Harrison. 1993. The Fetal Treatment Center. *Seminars in Pediatric Surgery*, 2(2):143-146.

Hubbard, Ruth, and Marian Lowe, ed. 1979. *Genes and Gender II: Pitfalls in Research on Sex and Gender.* New York: Gordian Press.

Hubbard, Ruth. 1990. *The Politics of Women's Biology*. New Brunswick: Rutgers University Press.

Hughes, Everett C. 1971. *The Sociological Eye: Selected Papers.* New Brunswick, NJ: Transaction Press.

Hulme, Keri. 1983. *The Bone People*. New York: Penguin Books.

Humphreys, Laud. 1970. *Tearoom Trade: A Study of Homosexual Encounters in Public Places*. New York: Aldine.

Huxley, Aldous. 1932. *Brave New World*. London: Chatto and Windus.

Institute of Medicine. 1994. *Fetal Research and Applications: A Conference Summary*. Washington, DC: National Academy Press.

Jennings, Russell W., Thomas E. MacGillivary, and Michael R. Harrison. 1993. Nitric Oxide Inhibits Preterm Labor in the Rhesus Monkey. *Journal of Maternal-Fetal Medicine*, 2:170-175.

Joffe, Carole. 1995. *Doctors of Conscience: The Struggle to Provide Abortion Before and After Roe v. Wade*. Boston: Beacon Press.

Johnsen, Dawn E. 1986. The Creation of Fetal Rights: Conflicts With Women's Constitutional Rights to Liberty, Privacy, and Equal Protection. *The Yale Law Journal*, 95(3):599-625.

Johnsen, Dawn. 1987. A New Threat to Pregnant Women's Autonomy. *Hastings Center Report*, August:33-40.

Johnson, John D., and Robert E. Greenberg. 1987. Regulation of Fetal Growth. In *Prenatal and Perinatal Biology and Medicine*, edited by Norman Kretchmer, Edward J. Quilligan, and John D. Johnson, 35-92. Chur: Harwood Academic Publishers.

Jones, James. 1993. The Tuskegee Syphilis Experiment: 'A Moral Astigmatism'. In *The 'Racial' Economy of Science: Toward a Democratic Future*, edited by Sandra Harding, 275-286. Bloomington: Indiana University Press.

Jordan, Kathleen, and Michael Lynch. 1992. The Sociology of a Genetic Engineering Technique: Ritual and Rationality in the Performance of the 'Plasmid Prep'. In *The Right Tools for the Job: At Work in Twentieth-Century Life Sciences*, edited by Adele E. Clarke, and Joan H. Fujimura, 77-114. Princeton: Princeton University Press.

Jost, Kenneth. 1989. Mother Versus Child. *ABA Journal*, April:84-88.

Karson, Evelyn M., and W. French Anderson. 1991. Prospects for Gene Therapy. In *The Unborn Patient: Prenatal Diagnosis and Treatment*, edited by Michael R. Harrison, Mitchell S. Golbus, and Roy A. Filly, 481-494. Philadelphia: W.B. Saunders Company.

Kaufmann, Caroline L., and Paul R. Williams. 1985. Fetal Surgery: The Social Implications of Medical and Surgical Treatment of the Unborn Child. *Women and Health*, 10(1):25-37.

Kertzer, David I. 1993. *Sacrificed for Honor: Italian Infant Abandonment and the Politics of Reproductive Control*. Boston: Beacon Press.

Kevles, Daniel J., and Leroy Hood, ed. 1992. *The Code of Codes: Scientific and Social Issues in the Human Genome Project*. Cambridge: Harvard University Press.

Kleinman, Sheryl. 1991. Field Workers' Feelings: What We Feel, Who We Are, How We Analyze. In *Experiencing Fieldwork*, edited by William B. Shaffier, and Robert A. Stebbins, 184-195. Newbury Park: Sage.

Knorr-Cetina, Karin. 1981. *The Manufacture of Knowledge: An Essay on the Constructivist and Contextual Nature of Science*. Oxford: Pergamon Press.

Koenig, Barbara A. 1988. The Technological Imperative in Medical Practice: The Social Creation of a 'Routine' Treatment. In *Biomedicine Examined*, edited by Margaret Lock, and Deborah R. Gordon, 465-496. Dordrecht: Kluwer Academic Publishers.

Kolata, Gina. 1990. *The Baby Doctors: Probing the Limits of Fetal Medicine*. New York: Delacorte Press.

Kolata, Gina. 1992. Transplants of Fetal Tissue Seen Easing a Brain Disease. *New York Times*, May 7, A14.

Koop, C.E. Everett. 1986. Editorial. *Fetal Therapy*, 1:1-2.

Korenbrot, Carol C., and Laura Gardner. 1991. Economic Considerations in Fetal Treatment. In *The Unborn Patient: Prenatal Diagnosis and Treatment*, edited by Michael R. Harrison, Mitchell S. Golbus, and Roy A. Filly, 25-35. Philadelphia: W.B. Saunders Company.

Koshland, Daniel E., Jr. 1989. Sequences and Consequences of the Human Genome. *Science*, 246(4927):189.

Kretchmer, Norman, Edward J. Quilligan, and John D. Johnson, ed. 1987. *Prenatal and Perinatal Biology and Medicine*. Chur: Harwood Academic Publishers.

Krummel, Thomas M., and Michael T. Longaker. 1991. Fetal Wound Healing. In *The Unborn Patient: Prenatal Diagnosis and Treatment*, edited by Michael R. Harrison, Mitchell S. Golbus, and Roy A. Filly, 526-536. Philadelphia: W.B. Saunders Company.

Langston, J. William, and Jon Palfreman. 1995. *The Case of the Frozen Addicts*. New York: Pantheon.

Laqueur, Thomas. 1990. *Making Sex: Body and Gender from the Greeks to Freud*. Cambridge: Harvard University Press.

Larson, Magali Sarfatti. 1990. In the Matter of Experts and Professionals, Or How Impossible It Is to Leave Nothing Unsaid. In *The Formation of Professions: Knowledge, State, and Strategy*, edited by R. Torstendahl, and M. Burrage, 24-50. London: Sage Publications.

Latour, Bruno , and Steve Woolgar. 1987. *Laboratory Life: The Social Construction of Scientific Facts*. Princeton: Princeton University Press.

Latour, Bruno. 1983. Give Me a Laboratory and I Will Raise the World. In *Science Observed: Perspectives on the Social Study of Science*, edited by Karin Knorr-Cetina, and Michael Mulkay, 141-170. Beverly Hills: Sage.

Latour, Bruno. 1987. *Science in Action: How to Follow Scientists and Engineers Through Society*. Cambridge: Harvard University Press.

Latour, Bruno. 1988. Mixing Humans and Nonhumans Together: The Sociology of a Door-Closer. *Social Problems*, 35(3):298-310.

Latour, Bruno. 1988. *The Pasteurization of France*. Cambridge: Harvard University Press.

Leary, Warren E. 1988. Panel Says Use of Fetal Tissue is 'Acceptable Public Policy'. New York Times, October 22,

Leary, Warren E. 1993. Waste is Found in Use of Prenatal Ultrasound. *New York Times*, September 16, A16.

Leavitt, Judith Walzer. 1986. *Brought to Bed: Childbearing in America, 1750-1950.* New York: Oxford University Press.

Leigh, Wilhelmina A. 1994. The Health Status of Women of Color. In *The American Woman 1994-95: Where We Stand [Women and Health]*, edited by Cynthia Costello, and Anne J. Stone, 154-196. New York: W.W. Norton & Company.

Lewin, Ellen, and Virginia Olesen, ed. 1985. *Women, Health, and Healing: Toward a New Perspective.* New York: Tavistock Publications.

Lewin, Tamar. 1987. Medical Use of Fetal Tissue Spurs New Abortion Debate. *New York Times*, August 16.

Liggins, Graham C. 1966a. Fetal Transfusion by the Impaling Technic. *OG*, 27(5):617-621.

Liggins, G.C. 1966b. A Self-Retaining Catheter for Fetal Peritoneal Transfusion. *Obstetrics and Gyncology*, 27(3):323-6.

Liggins, G.C. 1969. Premature Delivery of Fetal Lambs Infused with Glucocorticoids. *Journal of Endocrinology*, 45:515-523.

Liggins, G.C., and R.N. Howie. 1972. A Controlled Trial of Antepartum Glucocorticoid Treatment for Prevention of the Respiratory Distress Syndrome in Premature Infants. *Pediatrics*, 50(4):515-525.

Light, Donald W. 1994. Managed Care: False and Real Solutions. *Lancet*, 344:1197-99.

Liley, A.W. 1960. The Technique and Complications of Amniocentesis. *New Zealand Medical Journal*, 581-86.

Liley, A.W. 1961. Liquor Amnii Analysis in the Management of the Pregnancy Complicated by Rhesus Sensitization. *American Journal of Obstetrics and Gynecology*, 82(6):1359-70.

Liley, A.W. 1963. Amniotic Fluid. In *Modern Trends in Human Reproductive Physiology*, edited by H.M. Carey, 227-244. London: Butterworths.

Liley, A.W. 1964. The Technique of Foetal Transfusion in the Treatment of Severe Haemolytic Disease. *ANZOG*, 4:145-8.

Liley, A.W. 1965a. Amniocentesis. *New England Journal of Medicine*, 272:731-2.

Liley, A.W. 1965b. Fetal Transfusion. *Proceedings of the 10th Congress of the International Society of Blood Transfusion*, 929-932.

Liley, A.W. 1965c. Intrauterine Transfusion. *Jewish Memorial Hospital Bulletin*, 10(1-2):70-76.

Liley, A.W. 1965d. The Use of Amniocentesis and Fetal Transfusion in Erythroblastosis Fetalis. *Pediatrics*, 35(5):836-47.

Liley, A.W. 1968. Diagnosis and Treatment of Erythroblastosis in the Fetus. In *Advances in Pediatrics*, edited by S.Z. Levine, 29-63. Chicago: Year Book Medical Publishers, Inc.

Liley, A.W. 1969. Intrauterine Transfusion. Unpublished paper, Postgraduate School of Obstetrics and Gynaecology, University of Auckland, New Zealand.

Liley, A.W. 1971a. A Case Against Abortion. *A Liberal Studies Broadsheet*, 1-4.

Liley, A.W. 1971b. The Development of the Idea of Fetal Transfusion. *American Journal of Obstetrics and Gynecology*, 3:302-304.

Liley, A.W. 1971c. The Rights of the Fetus. Unpublished paper, Postgraduate School of Obstetrics and Gynecology, University of Auckland.

Liley, A.W. 1971d. *The Unborn Child.* Health, 12-13.

Liley, A.W. 1972a. Disorders of Amniotic Fluid. In *Pathophysiology of Gestation,* edited by 157-206. New York: Academic Press, Inc.

Liley, A.W. 1972b. The Foetus as a Personality. *Australia and New Zealand Journal of Psychiatry*, 6:99-105.

Liley, A.W. 1979. The Medical Reality of Achieving the Pro-Life Ideal. Presented at the national conference of the Society for the Protection of the Unborn Child, Wellington, New Zealand.

Liley, A.W. 1980a. Rh Haemolytic Disease: Peacekeeping on the Maternofetal Frontier. Presented in Long Beach, CA.

Liley, A.W. 1980b. The Social Integration of the Victim of Downs Syndrome. Unpublished paper, Postgraduate School of Obstetrics and Gynecology, University of Auckland.

Liley, A.W. 1982. Medical Research in Mental Retardation. Unpublished paper, Postgraduate School of Obstetrics and Gynecology, University of Auckland.

Liley, A.W. 1983. Development of Life. *Humanity*, July, 6-8.

Liley, A.W. 1986. The Fetus as a Personality [Originally published in 1972 in Australian and New Zealand Journal of Psychiatry, 6:99-105]. *Fetal Therapy*, 1:8-17.

Liley, A.W. n.d.a. The Humanity of the Unborn.

Liley, A.W. n.d.b. Physiological Problems in Foetal Transfusion. Unpublished paper, Postgraduate School of Obstetrics and Gynaecology, Auckland, New Zealand.

Liley, A.W. n.d.c. Prenatal Treatment of Haemolytic Disease: Sociomedical Aspects. Unpublished paper given at the Symposium of the Carlo Erba Foundation.

Liley, A.W. n.d.d. Rh Disease. Unpublished paper, Postgraduate School of Obstetrics and Gynaecology, University of Auckland, New Zealand.

Liley, A. William, and Brian Richard Boylan. 1965. The Expectant Mother: What the Rh Factor is and What Can Be Done About It. *Redbook*, 38-39.

Liley, H.M.I., and Beth Day. 1966. *Modern Motherhood: Pregnancy, Childbirth, and the Newborn Baby.* New York: Random House.

Lippman, A. 1992. Prenatal Diagnosis: Can What Counts Be Counted? *Women & Health*, 18(2):1-8.

Longaker, Michael T., and Leonard B. Kaban. 1991. Experimental Craniofacial Abnormalities. In *The Unborn Patient: Prenatal Diagnosis and Treatment,* edited by Michael R. Harrison, Mitchell S. Golbus, and Roy A. Filly, 590-597. Philadelphia: W.B. Saunders Company.

Longaker, Michael T., Mitchell S. Golbus, Roy A. Filly, Mark A. Rosen, Sophia W. Chang, and Michael R. Harrison. 1991. Maternal Outcome After Open Fetal

Surgery: A Review of the First 17 Cases. *Journal of the American Medical Association*, 265(6):737-741.

Longino, Helen E. 1990. *Science as Social Knowledge*. Princeton: Princeton University Press.

Longo, Lawrence D. 1978. An Appreciation of Donald Henry Barron. In *Fetal and Newborn Cardiovascular Physiology*, edited by Lawrence D. Longo, and Daniel D. Reneau, xxvii-xxxiv. New York: Garland STPM Press.

Louw, J.H. 1974. Wither Pediatric Surgery? *South African Medical Journal*, 48:1597-1598.

Luker, Kristin. 1984. *Abortion and the Politics of Motherhood*. Berkeley: University of California Press.

Lynch, Michael. 1988. Sacrifice and the Transformation of the Animal Body into a Scientific Object: Laboratory Culture and Ritual Practice in the Neurosciences. *Social Studies of Science*, 18:265-289.

Macdonald, Iain. 1973. Tree Surgeons Drop Their Scalpels and Hack Into It. *New Zealand Herald Weekend Magazine*.

Macklin, Ruth. 1990. Maternal-Fetal Conflict: An Ethical Analysis. *Women's Health Issues*, 1(1):28-30.

Manning, Frank A. 1995. *Fetal Medicine: Principles and Practice*. Norwalk, CT: Appleton & Lange.

Martin, Chester B., Jr., and Yuji Murata. 1988. Perspective on the Fetus. In *Nonhuman Primates in Perinatal Research*, edited by Yves W. Brans, and Thomas J. Kuehl, 275-280. New York: John Wiley and Sons.

Martin, Emily. 1987. *The Woman in the Body: A Cultural Analysis of Reproduction*. Boston: Beacon Press.

Martin, Emily. 1991. The Egg and the Sperm: How Science Has Constructed a Romance Based on Stereotypical Male-Female Roles. *Signs*, 16:485-501.

Marwick, Charles. 1993. Coming to Terms with Indications for Fetal Surgery. *Journal of the American Medical Association*, 270(17):2025, 2029.

Mattingly, Susan S. 1992. The Maternal-Fetal Dyad: Exploring the Two-Patient Obstetric Model. *Hastings Center Report*, Jan.-Feb.:13-18.

Maynard-Moody, Steven. 1984. The Fetal Research Dispute. In *Controversy: Politics of Technical Decisions*, edited by Dorothy Nelkin, 213-232. Newbury Park: Sage.

Maynard-Moody, Steven. 1995. *The Dilemma of the Fetus: Fetal Research, Medical Progress, and Moral Politics*. New York: St. Martin's Press.

McCarthy, Pat. 1983. A Legacy of Life. *Humanity*, July, 5.

McGourty, Christine. 1989. Ban on Use of Fetal Tissue to Continue. *Nature*, 342:105.

McKinlay, John B., ed. 1984. *Issues in the Political Economy of Health Care*. New York: Tavistock Publications.

Mead, George Herbert. 1934. *Mind, Self, and Society*. Chicago: University of Chicago Press.

Michejda, Maria, and Kevin Pringle. 1986a. Editorial. *Fetal Therapy*, 1:3-7.

Michejda, Maria, and Kevin Pringle. 1986b. Note from the Editors. *Fetal Therapy*, 1:8.

Mills, C. Wright. 1959. *The Sociological Imagination.* London: Oxford University Press.

Moise, Kenneth, Jr. 1993. Percutaneous Umbilical Blood Sampling. Presented at the Institute of Medicine Conference on Fetal Research and Applications, Irvine, CA, June 20-22.

Mol, Annemarie, and Marc Berg. 1996. Differences in Medicine: An Introduction. In *Differences in Medicine: Unraveling Practices, Techniques, and Bodies,* edited by Marc Berg, and Annemarie Mol, Cambridge: Harvard University Press, under review.

Moore, Lisa Jean. 1996. Producing Safer Sex: Knowledge, Latex, and Sex Workers in the Age of AIDS. Unpublished doctoral dissertation, Department of Social and Behavioral Sciences, University of California, San Francisco, forthcoming.

Morgan, Lynn M. 1989. When Does Life Begin? A Cross-Cultural Perspective on the Personhood of Fetuses and Young Children. In *Abortion Rights and Fetal Personhood,* edited by Ed Doerr, and James W. Prescott, 97-114. Long Beach, CA: Centerline Press.

Morgan, Lynn M. 1995. Fetal Relationality in Feminist Philosophy: An Anthropological Critique. *Hypatia*, forthcoming.

Morgan, Lynn M. n.d. Ambiguities Lost: Fashioning the Fetus Into a 'Child at Risk' in Ecuador and the United States. In *Mothers and Children at Risk,* edited by Carolyn Sargent, and Nancy Scheper-Hughes, Berkeley: University of California Press, forthcoming.

Morowitz, Harold J., and James S. Trefil. 1992. *The Facts of Life: Science and the Abortion Controversy.* New York: Oxford University Press.

Murata, Yuji, Shunichi Fujisaki, Chikara Endo, and Chester B. Martin Jr. 1988. Chronic Instrumentation of the Fetal Primate. In *Nonhuman Primates in Perinatal Research,* edited by Yves W. Brans, and Thomas J. Kuehl, 231-243. New York: John Wiley and Sons.

Murphy, Julien S. 1989. Should Pregnancies Be Sustained in Brain-Dead Women?: A Philosophical Discussion of Postmortem Pregnancy. In *Healing Technology: Feminist Perspectives,* edited by Kathryn Strother Ratcliff, 135-159. Ann Arbor: University of Michigan Press.

Natuzzi, E.S., P.C. Ursell, M. Harrison, C. Buscher, and R.K. Riemer. 1993. Nitric Oxide Synthase Activity in the Pregnant Uterus Decreases at Parturition. *Biochemical and Biophysical Research Communications*, 194(1):1-8.

Navarro, Vicente. 1986. *Crisis, Health, and Medicine: A Social Critique.* New York: Tavistock Publications.

Nelkin, Dorothy, ed. 1984. *Controversy: Politics of Technical Decisions.* Newbury Park: Sage.

Nelson, Lawrence J., and Nancy Milliken. 1990. Compelled Medical Treatment of Pregnant Women: Life, Liberty, and Law in Conflict. In *Ethical Issues in the New Reproductive Technologies,* edited by Richard T. Hull, 224-240. Belmont: Wadsworth Publishing Company.

Nelson, Robert M. 1990. A Policy Concerning the Therapeutic Use of Human Fetal Tissue in Transplantation. *Western Journal of Medicine*, 152:447-448.

New York Times. 1994. Clinton Limits U.S. Human Embryo Testing. *San Francisco Chronicle*, December 3.

Nilsson, Lennart. 1990. *A Child Is Born*. New York: Delta-Seymour Lawrence.

Oakley, Ann. 1984. *The Captured Womb: A History of the Medical Care of Pregnant Women*. Oxford: Basil Blackwell.

Olesen, Virginia, and Ellen Lewin. 1985. Women, Health, and Healing: A Theoretical Introduction. In *Women, Health, and Healing: A New Perspective*, edited by Ellen Lewin, and Virginia Olesen, 1-24. New York: Tavistock Publications.

Olesen, Virginia. 1994. Feminisms and Models of Qualitative Research. In *Handbook of Qualitative Research*, edited by Norman Denzin, and Yvonna Lincoln, 158-174. Newbury Park: Sage.

Oudshoorn, Nelly. 1994. *Beyond the Natural Body: An Archaeology of Sex Hormones*. London: Routledge.

Oudshoorn, Nelly, and Marianne Van Den Wijngaard. 1991. Dualism in Biology: The Case of Sex Hormones. *Women's Studies International Forum*, 14(5):459-471.

Overall, Christine. 1990. Selective Termination of Pregnancy and Women's Reproductive Autonomy. *Hastings Center Report*, 20(3):6-12.

Palca, Joseph. 1989. Fetal Tissue Transplants Remain Off Limits. *Science*, 246:752.

Palca, Joseph. 1991. Fetal Brain Signals Time for Birth. *Science*, 253:1360.

Palca, Joseph. 1992. Banking for Transplantation Research. *Science*, 256(May 29):1274.

Park, Robert Ezra. 1952. *Human Communities*. Glencoe, IL: Free Press.

Parsons, Talcott. 1975. The Sick Role and the Role of the Physician Reconsidered. *Milbank Memorial Fund Quarterly*, Summer:257-278.

Perrin, Karen M. 1993. Informed Consent: Responsibility and Accountability in Medical Research. Unpublished abstract, College of Public Health, University of South Florida.

Petchesky, Rosalind Pollack. 1987. Fetal Images: The Power of Visual Culture in the Politics of Reproduction. In *Reproductive Technologies: Gender, Motherhood, and Medicine*, edited by Michelle Stanworth, 57-80. Minneapolis: University of Minnesota Press.

Petchesky, Rosalind Pollack. 1990. *Abortion and Woman's Choice: The State, Sexuality, and Reproductive Freedom*. Boston: Northeastern University Press.

Pickering, Andrew, ed. 1992b. *Science as Practice and Culture*. Chicago: University of Chicago Press.

Pickering, Andrew. 1992a. From Science as Knowledge to Science as Practice. In *Science as Practice and Culture*, edited by Andrew Pickering, 1-26. Chicago: University of Chicago Press.

Pringle, Kevin C. 1986. Fetal Surgery: It Has a Past, Has It a Future? *Fetal Therapy*, 1:23-31.

Proctor, Robert N. 1988. *Racial Hygiene: Medicine Under the Nazis.* Cambridge: Harvard University Press.

Purdy, Laura M. 1990. Are Pregnant Women Fetal Containers? *Bioethics*, 4(4):273-291.

Rabinow, Paul. 1992. Studies in the Anthropology of Reason. *Anthropology Today*, 8(5):7-10.

Rader, Karen. 1995. Making Mice: C.C. Little, the Jackson Laboratory, and the Standardization of *Mus Musculus* for Research. Unpublished doctoral dissertation, Department of History and Philosophy of Science, Indiana University.

Ramirez de Arellano, Annette B., and Conrad Seipp. 1983. *Colonialism, Catholicism, and Contraception: A History of Birth Control in Puerto Rico.* Chapel Hill: University of North Carolina Press.

Rapp, Rayna. 1984. XYLO: A True Story. In *Test-Tube Women: What Future for Motherhood?*, edited by Rita Arditti, Renate Duelli Klein, and Shelley Minden, 313-328. London: Pandora Press.

Rapp, Rayna. 1990. Constructing Amniocentesis: Maternal and Medical Discourses. In *Uncertain Terms: Negotiating Gender in American Culture*, edited by Faye Ginsburg, and Anna Lowenhaupt Tsing, 28-42. Boston: Beacon Press.

Rapp, Rayna. 1993a. Accounting for Amniocentesis. In *Knowledge, Power, and Practice: The Anthropology of Medicine in Everyday Life*, edited by Shirley Lindenbaum, and Margaret Lock, Berkeley: University of California Press.

Rapp, Rayna. 1993b. Amniocentesis in Sociocultural Perspective. *Journal of Genetic Counseling*, 2:183-196.

Rapp, Rayna. 1993c. Ethnocultural Diversity and Genetic Counseling Training: The Challenge of the 21st Century. *Journal of Genetic Counseling*, 2:155-58.

Rapp, Rayna. 1993d. Risky Business: Genetic Counseling in a Shifting World. In *Reproductive Histories*, edited by Jane Sivedro, and Rayna Rapp, Berkeley: University of California Press.

Rapp, Rayna. 1994. Women's Responses to Prenatal Diagnosis: A Sociocultural Perspective on Diversity. In *Women and Prenatal Testing: Facing the Challenges of Genetic Technology*, edited by Karen Rothenberg, and Elizabeth Thompson, Columbus: University of Ohio Press.

Rawlins, Richard G., and Matt J. Kessler. 1986. The History of the Cayo Santiago Colony. In *The Cayo Santiago Macaques: History, Behavior, and Biology*, edited by Richard G. Rawlins, and Matt J. Kessler, 13-45. Albany: SUNY Press.

Redmond, Eugene. 1991. The Critical Need for Fetal Tissue Transplantation Research. In *The Politics of Abortion: The Impact on Scientific Research*, edited by National Abortion Rights Action League Foundation, 13-14. Washington, DC: Bass and Howes.

Reid, Tony. 1973. Seeing Children As People. *New Zealand Listener*, September 10, 8.

Reiser, Stanley Joel. 1982. *Medicine and the Reign of Technology.* Cambridge: Cambridge University Press.

Reiser, Stanley Joel , and Michael Anbar. 1986. *The Machine at the Bedside: Strategies for Using Technology in Patient Care.* Cambridge: Cambridge University Press.

Reverby, Susan, and David Rosner. 1979. Beyond the Great Doctors. In *Health Care in America,* edited by 3-16. Philadelphia: Temple University Press.

Riessman, Catherine Kohler. 1983. Women and Medicalization: A New Perspective. *Social Policy*, 14:3-18.

Roberts, Leslie. 1991. FISHing Cuts the Angst in Amniocentesis. *Science*, 254(October 18):378-379.

Rosaldo, Renato. 1989. *Culture and Truth: The Remaking of Social Analysis.* Boston: Beacon Press.

Rosenberg, Charles. 1979. Toward an Ecology of Knowledge: On Discipline, Context, and History. In *The Organization of Knowledge in Modern America, 1860-1920,* edited by Alexandra Oleson, and John Voss, 440-455. Baltimore: Johns Hopkins University Press.

Rosenberg, Charles. 1988. Woods or Trees? Ideas and Actors in the History of Science. *ISIS*, 79:565-570.

Rossiter, Margaret W. 1982. *Women Scientists in America: Struggles and Strategies to 1940.* Baltimore: Johns Hopkins University Press.

Roth, Julius. 1974. Professionalism: The Sociologist's Decoy. *Sociology of Work and Occupations*, 1(1):6-23.

Rothenberg, Karen H., and Elizabeth J. Thomson, ed. 1994. *Women and Prenatal Testing: Facing the Challenges of Genetic Technology.* Columbus: Ohio State University Press.

Rothman, Barbara Katz. 1986. *The Tentative Pregnancy: Prenatal Diagnosis and the Future of Motherhood.* New York: Penguin Books.

Rothman, Barbara Katz. 1989. *Recreating Motherhood: Ideology and Technology in a Patriarchal Society.* New York: W.W. Norton & Company.

Rothman, Barbara Katz. 1991. Prenatal Diagnosis. In *Biomedical Ethics Reviews,* edited by J. Humber, and R. Almeder, 171-187. Totowa, NJ: Humana Press, Inc.

Rouse, Joseph. 1993. What are Cultural Studies of Scientific Knowledge? *Configurations*, 1(1):1-22.

Rowland, Robyn. 1992. *Living Laboratories: Women and Reproductive Technologies.* Bloomington: Indiana University Press.

Ruddick, Sara. 1980. Maternal Thinking. *Feminist Studies*, 6:342-364.

Ruzek, Sheryl. 1978. *The Women's Health Movement: Feminist Alternatives to Medical Control.* New York: Praeger.

Ryan, Kenneth J. 1990. Erosion of the Rights of Pregnant Women: In the Interest of Fetal Well-Being. *Women's Health Issues*, 1(1):21-24.

Saltus, Richard. 1981. Successful Surgery on Unborn Child. *San Francisco Examiner*, July 26, 1.

Saltus, Richard. 1995. Pig Brain Tissue Implanted in Human Patient. *San Francisco Chronicle*, April 20, A4.

Saxton, Marsha. 1984. Born and Unborn: The Implications of Reproductive Technologies for People with Disabilities. In *Test-Tube Women: What Future for Motherhood?*, edited by Rita Arditti, Renate Duelli Klein, and Shelley Minden, 298-312. London: Pandora Press.

Scheerer, Lourdes J., and Michael Katz. 1991. Tocolysis for Fetal Intervention. In *The Unborn Patient: Prenatal Diagnosis and Treatment*, edited by Michael R. Harrison, Mitchell S. Golbus, and Roy A. Filly, 182-188. Philadelphia: W.B. Saunders.

Scheper-Hughes, Nancy. 1992. *Death Without Weeping: The Violence of Everyday Life in Brazil*. Berkeley: University of California Press.

Schiebinger, Londa. 1989. *The Mind Has No Sex? Women in the Origins of Modern Science*. Cambridge: Harvard University Press.

Schulman, Joseph D., and Mark I. Evans. 1991. The Fetus with a Biochemical Defect. In *The Unborn Patient: Prenatal Diagnosis and Treatment*, edited by Michael R. Harrison, Mitchell S. Golbus, and Roy A. Filly, 205-209. Philadelphia: W.B. Saunders.

Seiger, Ake. 1989. Collection and Use of Fetal Central Nervous System Tissue. *Fetal Therapy*, 4(1):104-107.

Shadbolt, Maurice. 1976. *Love and Legend*. [Unknown publisher.]

Sherwin, Susan. 1992. *No Longer Patient: Feminist Ethics and Health Care*. Philadelphia: Temple University Press.

Skerrett, P.J. 1991. Wound Healing in the Womb. *Science*, 252:1066.

Stabile, Carol. 1992. Shooting the Mother: Fetal Photography and the Politics of Disappearance. *Camera Obscura*, 28:179-206.

Stacey, Margaret. 1984. Who Are the Health Workers? Patients and Other Unpaid Workers in Health Care. *Economic and Industrial Democracy*, 5:157-184.

Stafford, Barbara Maria. 1991. *Body Criticism: Imaging the Unseen in Enlightenment Art and Medicine*. Cambridge: MIT Press.

Stanworth, Michelle. 1987. Reproductive Technologies and the Deconstruction of Motherhood. In *Reproductive Technologies: Gender, Motherhood, and Medicine*, edited by Michelle Stanworth, 10-35. Minneapolis: University of Minnesota Press.

Star, Susan Leigh. 1983. Simplification in Scientific Work: An Example from Neuroscience Research. *Social Studies of Science*, 13:208-226.

Star, Susan Leigh. 1985. Scientific Work and Uncertainty. *Social Studies of Science*, 15:391-427.

Star, Susan Leigh. 1986. Triangulating Clinical and Basic Research: British Localizationists, 1870-1906. *History of Science*, 24:29-48.

Star, Susan Leigh. 1991. The Sociology of the Invisible: The Primacy of Work in the Writings of Anselm Strauss. In *Social Organization and Social Process: Essays in Honor of Anselm Strauss*, edited by David R. Maines, 265-283. Hawthorne: Aldine de Gruyter.

Star, Susan Leigh, and James R. Griesemer. 1989. Institutional Ecology, 'Translations' and Boundary Objects: Amateurs and Professionals in Berkeley's Museum of Vertebrate Zoology, 1907-39. *Social Studies of Science*, 19:387-420.

Starr, Paul. 1982. *The Social Transformation of American Medicine*. New York: Basic Books.

Steinbock, Bonnie. 1992. *Life Before Birth: The Moral and Legal Status of Embryos and Fetuses*. New York: Oxford University Press.

Stepan, Nancy. 1986. Race and Gender: The Role of Analogy in Science. *Isis*, 77:261-277.

Stith-Coleman, Irene. 1993. *Human Fetal Research and Tissue Transplantation.* Congressional Research Service, Library of Congress.

Strauss, Anselm. 1978. *Negotiations: Varieties, Contexts, Processes, and Social Order*. San Francisco: Jossey-Bass.

Strauss, Anselm. 1987. *Qualitative Analysis for Social Scientists*. New York: Cambridge University Press.

Strauss, Anselm. 1988. The Articulation of Project Work: An Organizational Process. *Sociological Quarterly*, 29(2):163-178.

Strauss, Anselm. 1991. *Creating Sociological Awareness: Collective Images and Symbolic Representations*. New Brunswick, NJ: Transaction Publishers.

Strauss, Anselm L. 1993. *Continual Permutations of Action*. New York: Aldine de Gruyter.

Strauss, Anselm, and Juliet Corbin. 1990. *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*. Newbury Park, CA: Sage.

Strauss, Anselm, Shizuko Fagerhaugh, Barbara Suczek, and Carolyn Wiener. 1982. The Work of Hospitalized Patients. *Social Science and Medicine*, 16:977-986.

Strauss, Anselm, Shizuko Fagerhaugh, Barbara Suczek, and Carolyn Wiener. 1985. *Social Organization of Medical Work*. Chicago: University of Chicago Press.

Strauss, Anselm, Leonard Schatzman, Rue Bucher, Danuta Erlich, and Melvin Sabshin. 1964. *Psychiatric Ideologies and Institutions*. Glencoe, IL: Free Press.

Strong, Carson. 1991. Fetal Tissue Transplantation: Can It Be Morally Insulated from Abortion? *Journal of Medical Ethics*, 17:70-76.

Taylor, Janelle Sue. 1993. The Public Fetus and the Family Car: From Abortion Politics to a Volvo Advertisement. *Science as Culture*, 3(4):601-618.

Terry, Jennifer. 1988. The Body Invaded: Medical Surveillance of Women as Reproducers. *Socialist Review*, 89(3):13-43.

Terry, Jennifer. 1990. Lesbians Under the Medical Gaze: Scientists Search for Remarkable Differences. *Journal of Sex Research*, 27(3):317-339.

Thomas, William I. 1978. The Definition of the Situation. In *Social Deviance,* edited by Ronald Farrell, and Victoria Swigert, 54-57. Philadelphia: Lippincott.

Thomas, William I., and Dorothy Swaine Thomas. 1970. Situations Defined as Real are Real in Their Consequences. In *Social Psychology Through Symbolic Interaction,* edited by Gregory P. Stone, and Harvey A. Farberman, 154-155. Waltham, MA: Xerox Publishers.

Thong, Y.H., and S.C. Harth. 1991. The Social Filter Effect of Informed Consent in Clinical Research. *Pediatrics*, 87(4):568-569.

Thorne, Emanuel D., and Maria Michejda. 1989. Fetal Tissue from Spontaneous Abortions: A New Alternative for Transplantation Research? *Fetal Therapy*, 4:37-42.

Tobach, Ethel, and Betty Rosoff, ed. 1978. *Genes and Gender I: First in a Series on Hereditarianism and Women.* New York: Gordian Press.

Tobach, Ethel, and Betty Rossoff. 1980. *Genes and Gender III: Genetic Determinism and Children.* New York: Gordian Press.

Todd, Alexandra Dundas. 1989. *Intimate Adversaries: Cultural Conflict Between Doctors and Women Patients.* Philadelphia: University of Pennsylvania Press.

Torstendahl, Rolf. 1990. Essential Properties, Strategic Aims, and Historical Development: Three Approaches to Theories of Professionalism. In *Professions in Theory and History: Rethinking the Study of the Professions,* edited by M. Burrage, and R. Torstendahl, 44-61. London: Sage Publications.

Traweek, Sharon. 1988. *Beamtimes and Lifetimes: The World of High Energy Physicists.* Cambridge: Harvard University Press.

Traweek, Sharon. 1992. Border Crossings: Narrative Strategies in Science Studies and Among Physicists in Tsukaba Science City, Japan. In *Science as Practice and Culture,* edited by Andrew Pickering, 429-466. Chicago: University of Chicago Press.

Weber, Max. 1949. *The Methodology of the Social Sciences.* New York: The Free Press.

West, Candace. 1984. *Routine Complications: Troubles with Talk Between Doctors and Patients.* Bloomington: Indiana University Press.

Zimmerman, David R. 1973. *Rh: The Intimate History of a Disease and Its Conquest.* New York: Macmillan Publishing Co., Inc.

Zola, Irving K. 1973. Pathways to the Doctor: From Person to Patient. *Social Science and Medicine*, 7:677-689.

Zola, Irving Kenneth. 1986. Medicine as an Institution of Social Control. In *The Sociology of Health and Illness,* edited by Peter Conrad, and Rochelle Kern, 379-390. New York: St. Martin's Press.