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## Prologue

A unique procedure begs an unusual presentation. I hope that this book, and the emotions that run through it, offer you that. My intention is to merge scholarly literatures with the personal hopes and fears of fetoscopy patient-parents and those who care for them, to enhance understanding of the social and cultural (or, *sociocultural*) context of in utero fetal surgery, or “*fetoscopy*.”

I witnessed my first fetoscopy in spring 1993, less than a year into my graduate program in Science and Technology Studies at Rensselaer Polytechnic Institute in Troy, New York. As a young graduate student interested in medicine, science, and technology, I willingly complied when my professor recommended that I attend a bioethics conference jointly sponsored by the nearby Albany Law School-Union University and Albany Medical College. I headed to the conference unaware that the course of my studies and life were about to change.

Although initially excited by the bioethical topics, I grew weary as the day progressed. As presenter after presenter took the stage to discuss issues of privacy, autonomy, and rights, I found myself easily distracted. Though each topic was interesting, the totality of the conference was overwhelming. I wanted to leave early, but knew that I could not. Not only would my professor expect a synopsis of the day, more to the point, I sat in the middle of a lecture row and could not sneak out without causing embarrassing disruptions. I let my mind wander in failing attempts to daydream the remaining afternoon away. It was toward the end of day that I saw a television and VCR wheeled center stage. My curiosity returned. Looking back, I acknowledge the sacred student realization, “*A movie!*”

Without much fan-fare, a video began: an in utero fetus appeared on the screen. It was flesh toned and moving. It was alive. I was mesmerized and could not look away. The presenter discussed the technique by which he captured the images, a procedure he called “embryofetoscopy” or “fetoscopy.”<sup>1</sup> He explained that the procedure combined tiny needles and endoscopes to reach inside a pregnant woman’s uterus whereupon he could make medical diagnoses on a fetus. As he explained the technique and his hopes for the future, I stared intently at the screen; I was peering inside some woman’s uterus, seeing a fetus that was yet to be born. Questions raced through my mind: Whose was it? Where was it headed? Was it going to live? These questions have not stopped. Following the presentation, I returned, renewed, to my studies and immediately set my energies toward exploring this technique. I read medical journals with zeal and confusion. I became interested in reproductive politics. I became obsessed with scopes and fetuses. I became obsessed with fetoscopy.

This book is the outcome of my studies; it is the creation of obsession and fascination. The work is intended to offer glimpses into the sometimes conflicted, often desperate, and always emotional lives of those undergoing and offering fetoscopy. To accomplish this task, I explore the multiple explanations surrounding fetoscopy development and use to understand better the processes through which, and reasons by which, individuals experience and build these powerful procedures, and the corollary, how these procedures affect individuals. My examination highlights the ways in which fetoscopy develops its many, and at times divergent, social and cultural meanings. This book is intended to give readers the opportunity to get to know what it is like to undergo a procedure and what it is like to build the fetoscopy experience. Therefore, it not only discusses the emotional work and experiences of patient-mothers, their companions, and physicians and nurses, but also is the product of my emotional work.<sup>2</sup> Within the following pages, I strive to take account of my emotions and those of the individuals who worked with me in researching this topic and becoming involved in the lives of those closest to fetoscopy. My hope is that this book will make a difference in the continued development and delivery of fetoscopy procedures and by so doing will help create medical protocols and improve individual experiences with the techniques.<sup>3</sup>

Fetoscopy is little known in nonmedical venues. When I interviewed patient-parents about their experiences and asked why they agreed to be interviewed, a number of respondents explained that they wanted other people (especially potential patients) to be familiar with this newly emergent technology. Many found it difficult to find information on fetoscopy, and as a result struggled through not only learning about their medical ailments, but also learning about the possible medical procedures to treat their conditions. In answer to these interviewees, and as noted earlier, I hope that this book will familiarize the reader with fetoscopy and its current and potential uses. As reproductive politics continue to take center stage in popular culture and U.S. politics, I hope this book will serve as an entry point for a number of readers to examine their own reproductive decisionmaking as well as that of others.

I join feminists who challenge readers to rethink or reframe how they envision “choosing” to alter fetal development in utero. There are many explanations for the meanings attributed to altering a pregnancy. As pregnancies and pregnancy decisions become more public, it is important to ask what is happening, to whom, and why. By drawing from examples of fetoscopy decision-making, this book highlights the difficulty of making decisions and living with and through the outcomes. This book joins a growing literature challenging the assumption that feminism is at odds with women who pursue fetal treatments that transgress their own bodies for the sake of the fetus within.

As chapter 2 details, this research is ethnographic. From 1997 to 1998, I conducted social scientific research at a small Catholic, women’s hospital, “Holy Names Hospital,” to learn how they created and delivered fetoscopy procedures. I watched surgeries and interviewed those who came in contact with the newly emergent technology. I worked alongside health care providers to understand better the technological, social, and cultural complexities of their techniques.

Since that time, I have watched this fetoscopy research team grow from a fledgling group of healthcare providers at a small community-based hospital into a world-renowned program. In May 2005, I returned to the hospital to check on the department’s development. All seemed well.

The practice had grown, new offices been built, and a large sign outside the hospital included the program as a department.

Less than six months after that visit, I received a phone call from the Fetoscopy Research Coordinator, a good friend of mine. Her usually jovial tone was gone as she simply said, “I have something to tell you. Are you sitting down?” My heart raced as I thought of every terrible thing that could befall any one of my friends in the department. I assured her I was sitting down. She continued, “We aren’t doing fetoscopy anymore. The department is closed and the doctor is leaving for another hospital.” I was in shock.<sup>4</sup> Though I always knew that fetoscopy was an odd fit at a community-based hospital, it nonetheless fit. For nine years use of fetoscopy at the hospital had grown, and just when it appeared to be taking off, it was gone.

Following years of development in a small Catholic women’s hospital, some of the medical professionals associated with fetoscopy, notably Marc Martinez (a world renowned leader in fetoscopy) moved his practice, and thus fetoscopy, to a large research and teaching hospital. Martinez and two other members of the “fetoscopy team” left the familiarity of Holy Names and set off to another hospital—one more familiar with cutting-edge surgery and medical technology development. This change will no doubt affect how fetoscopy is delivered in the future; however, many of the ways in which fetoscopy began to “stabilize” as a medical procedure happened during its development at Holy Names (Bijker, Hughes, and Pinch 1987). The medical procedures and social environments that are fetoscopy will now be recast at this larger university hospital. The intriguing question to be explored over the next decade of fetoscopy development is how much will the university hospital alter fetoscopy delivery and how will fetoscopy delivery (including those who create and undergo it) alter the university hospital? If hospitals have embedded institutional histories, perhaps, fetoscopy does, too. Perhaps the ways in which the fetoscopy team developed the procedures and the social interactions that surrounded and sustained it at Holy Names will, in turn, alter the research hospital in which it will continue to grow.

It is likely that many of the patient issues that arise in the community-based setting will not alter as women now undergo fetoscopy at a large hospital (e.g., experiencing confusion, fear, blame, and guilt); however,

some aspects of the policies governing patient care will change. What is most important for this analysis, however, is to recognize that during the nine years in which fetoscopy was not in a research hospital, it did develop and it did affect those around it. These effects are part of the history of fetoscopy development and carry with it into this new setting. This unexpected turn of events makes knowing what happened at the community-based hospital even more consequential.

It is imperative that this book offer as many inroads as possible to understand the lived experience of these procedures. There are many potential readers: medical staff, ethicists, social scientists, students, and patients, to name a few. Each brings particular questions and assumptions regarding fetoscopy efficacy and reproductive procedures and politics. The format of this book is designed with reader differences in mind. I hope to add to social scientific literature using as little academic jargon as possible to enable medical professionals, pregnant women, and an interested public a chance to get to know a fetoscopy site and to feel some of the hope and despair that is a daily part of fetoscopy care-giver and patient lives. Though the scholarly literatures in which this analysis is based lie at the intersection of science and technology studies, bioethics, and medical anthropology, the manner in which it is written seeks to transgress these fields and professional boundaries.

To reach this wide-ranging audience with clearly stated social analytic tools, I break from academic convention and begin this book with a short story. It is not social theory, explicit critique, or interview analysis. Fetoscopy is an emotional experience. It is also exciting, cutting-edge medical technology. It is easy to become lost in the hype of “new frontiers” and “miracle babies” and lose sight of the real lives that are touched by these powerful, life-changing procedures. As I studied fetoscopy, I began to wonder how I might convey the emotion of these events to readers who likely did not know anyone who had undergone a procedure. As I watched and listened, I wondered, what would lead an otherwise healthy woman to consent to surgery? What would lead physicians and nurses to pursue medical technology development with such determination? As I learned more, and this book will show, there were no simple answers. While each patient and experience was unique, one thing remained constant in all fetoscopy cases: fetoscopy was and

remains emotional work. Each case was at once private and public, intimate and extrinsic. As patients passed through our doors their faces began to blend, but their words and experiences stood out and hit chords with even the most emotionally detached fetoscopy team members. As each day of my study passed I wondered, how will I report this in a way that captures this essence?

In an effort to help readers *get to know* fetoscopy as a real procedure with emotional impacts, the first chapter offers an account of a couple undergoing a surgery, Melinda and Joe. The story is based on an amalgamation of people that I met while conducting this research. The reason for this chapter must be made clear: *fetoscopy is a real procedure that affects real people*. I do not want this book to use interview material that is easily forgotten as the next words are read or the next woman tells part of her story. To understand fetoscopy, every reader should have the opportunity to “meet” someone who has undergone the procedure and to be with her through her experiences. I hope that you come to know Melinda and Joe, and keep them in mind as you read the remainder of this book. Following this chapter, every quote is offered by individuals who consented to be interviewed about their experiences. To ensure confidentiality, the first chapter is intended to help you feel the investment that those cited within this book have made in their fetoscopic experiences.

Following the story of Melinda and Joe, chapter 2, “Why Fetoscopy? Why Now?: Ethnography of a Medical Technology and the Emotions that Fuel It,” details the methodology used in this work and my personal politics that, in part, fueled the study. I outline a history of fetoscopy starting in the 1970s and explore the reasons why fetoscopy never took off as a reproductive procedure until the early 1990s, and even now continues to struggle to find a place in high-risk obstetrical care (perinatology). This chapter marks the beginning of social science critique of fetoscopy and acts as the foundation on which the remainder of the book rests.

Chapter 3, “Fetoscopy in Cultural Context: Fetal Politics, Reproductive Choice, Religious Experiences and Maternal Blame and Failure,” follows the questions of why and how fetoscopy emerged and how I came to study it while broadening the discussion of fetoscopy into larger

social and cultural concerns. I examine the history and current context that makes fetoscopy a viable prenatal procedure in the twenty-first century at a community-based hospital. Further, I explore how fetoscopy and reproductive politics are borne out in Catholic doctrine, and more important, at Holy Names Hospital. I also examine the role of maternal blame and failure in leading pregnant women to consent to fetoscopy. This chapter addresses larger contextual issues that frame fetoscopy use in general (as well as adds individual interview material) to offer a fuller examination of how and why fetoscopy development occurs in some medical establishments and addresses some of the positive and negative effects of its use.

Chapter 4, “How to Create a Fetoscopy Collective: Define the Risks and Find Participants,” turns from broad social analysis offered in the previous chapter to investigate the ways in which fetoscopy workers at Holy Names have come to accept or reject the procedure within their hospital. This chapter continues the themes of religion from the previous chapter (how and why fetoscopy develops at Holy Names Hospital) and introduces the notion of “risk” as experienced by pregnant women and those who care for them. I explore how and why Holy Names trains other medical professionals internally and externally (e.g., publications and research) to move fetoscopy from the fringes of medical development and use to become an integral part of hospital practices and ultimately to develop into a world-renowned center for fetal therapy.

Chapter 5, “Fetoscopy and the Single Fetus: Diagnostic Embryofetoscopy, Bladder Obstruction, Amniotic Band Syndrome, and the Technological Fix,” is an analysis of the many ways in which fetoscopy is used on singleton pregnancies (one fetus). Although fetoscopy is generally used for twinning gestations, it also offers single fetuses potential treatment options. This chapter presents a general discussion of the possibilities of diagnostic procedures including its potential for genetic therapy, and links it with a discussion of treating unusual singleton conditions (i.e., boutique medicine and orphan conditions). I examine the importance of visualization in some perinatology advances and use two case studies to explore its use: amniotic band syndrome and bladder obstructions. Following these discussions I address the “Achilles’ heel” of fetoscopy: amniotic membrane rupture (Deprest, Lerut, and

Vandenbergh 1997). Although fetoscopy may embody great hope for otherwise lost pregnancies, until the side effects of its use are better understood and controlled, its potential place in perinatology and continued advancement and proliferation cannot be assured. By examining a variety of ways in which fetoscopy is currently used and ending with its frailty, this chapter highlights the many ways fetoscopy can be used while underscoring that for all the hype and hope for the technique, a seemingly simple, yet medically complex side effect may limit its development.

Chapter 6, “Ligation and Twins: Making and Choosing Twins in High-Risk Pregnancy,” introduces the most common use of fetoscopy: to separate identical twins in utero when one fetus increases ailments of the other. Utilizing cases studies of two conditions, twin-to-twin transfusion syndrome and acardiac twinning, I explore the metaphorical doppelganger of one twin feeding off its co-twin to survive (c.f., Strauss 1996). In this chapter, I examine how women and their caregivers come to know these in utero entities and what place religion, culture, and society as well as medical science play in determining who or what a pregnant woman carries inside her and what are acceptable treatment options for these conditions. This chapter continues themes of religion and visualization from previous chapters (e.g., how personhood is created in the context of fetal technologies and visualization) and expands it into discussions of rare twinning conditions.

Chapter 7, “Loss and Success: Social Networks and Constructing an Outcome,” examines “what counts” as a success and what it means to suffer a loss. As evidenced in the previous chapters, I argue that all fetoscopy procedures are carried out in, and shaped by, a context of loss. It falls to the individual woman and her social network to find creative, emotional, and at times conflicting narratives to make sense of what seems too often to be a senseless situation. I argue that all losses (of all sorts) are in fact full of meaning and sense; however, it is only in finding a place to speak about such loss, and developing policies to reflect and accept such loss, that fetoscopy patients may ultimately find a sense of relief.

Chapter 8, “Final Thoughts on Fetoscopy,” offers a summary of fetoscopy and a look toward the future of these continually developing procedures. Here I address my own political concerns surrounding

fetoscopy proliferation and my hope that its ultimate use be informed by some of the findings and themes presented in this work.

As the first social scientific analysis based solely on fetoscopy development, use, and effect, this book covers a wide range of fetoscopy issues, including its history and the varied uses physicians pursue today as well as some exciting, yet questionable, possible uses for it in the future. Throughout this book, themes such as risky decision-making, moral and religious contexts, as well as individual hope and fear will appear. Each chapter relies on these themes; however, depending on the particular chapter some themes will emerge more clearly than others. Taken together, though, these themes form the sociocultural backdrop on which fetoscopy development and use play out. It ultimately falls to the individuals interacting with fetoscopy to form an environment in which fetoscopy does or does not make sense. This work makes these interactions and environments visible.

### A Note on the Conditions

Fetoscopy can be used on singleton and multiple gestations as a diagnostic and operative procedure. Although each condition will be explained within this book, it is useful to offer a short summary here of the conditions that I will discuss in the remaining chapters. Although relatively few conditions are amenable to fetoscopic diagnosis and therapy, the list continues to grow. Many conditions appear in this book, however, most often cited are the following:<sup>5</sup>

*Bladder Obstruction* Approximately 1:5000–8000 male fetuses develop blockages in the urethra. If the blockage is not relieved, severe kidney damage and decreased urination may ensue, leading to low levels of amniotic fluid. Decreased amniotic fluid hinders lung development and may lead to in utero death. With operative fetoscopy, physicians insert a small needle and scope device in utero to identify the blockage and, if possible, fix it. Without treatment, 30 to 50% of the fetuses die shortly before or after birth.

*Acardiac Twinning* An extremely rare condition affecting 1:35,000 pregnancies, acardiac twins are identical twins in which the zygote split

relatively late in gestation. With this late separation, one twin generally develops “normal” physiology and characteristics while the other twin does not. The acardius lacks or has a rudimentary heart (therefore the name “a”-“cardiac”), and often also lacks a head and/or arms. The result is that the “healthy” twin’s heart acts as a pump for both twins and ultimately expends itself due to the high pumping rate. This problem is compounded by the acardius’ physiology, which tends to bloat with excess blood, while the “pump” twin slowly grows anemic. If left untreated, approximately 50 to 75% of these pregnancies end in the loss of the viable co-twin. With fetoscopic ligation (tying off an umbilical cord) the success rate for a live birth increases to 70 to 80%.

*Twin-to-Twin Transfusion Syndrome (TTTS)* Approximately 6000 fetuses are affected with TTTS per year and 4000 will die.<sup>6</sup> Similar to acardiac twinning, TTTS is a rare condition affecting identical twin fetuses in which the fetuses share blood disproportionately. The uneven sharing of blood leads one twin to grow anemic, while the other bloats with excess blood. At the same time the fetus receiving excess blood urinates at a higher frequency, leading to increased amniotic fluid in one amniotic sac (assuming they are in separate sacs; in rare cases they share a sac). The anemic fetus is unable to urinate and its amniotic sac does not fill with amniotic fluid. The low amount of amniotic fluid makes the twin appear to be “stuck” against the uterine wall while the co-twin’s amniotic sac fills at a dangerous rate. TTTS can lead to neurological damage or death of one or both fetuses. Fetoscopy combined with in utero laser surgery, (photocoagulation) of the shared placenta disrupts the blood flow and may separate one fetal circulation from the other.<sup>7</sup> With laser surgery, success rates for one live baby is 74 to 80%, with a 4% rate of cerebral palsy (if the co-twin dies in utero). In severe cases in which one fetus is no longer viable, ligation of the dying fetus is an option.<sup>8</sup> With ligation, the success rate for one live baby is 90%; however, it remains possible that the survivor may suffer neurological or other impairments.

*Amniotic Band Syndrome* A condition affecting approximately 1:1200 to 1:1500 live births, amniotic band syndrome is still not well understood and competing medical theories exist (Quintero, 2002c). However, a leading argument is that lesions develop in utero and adhere to the

developing embryo-fetus. These materials wrap around the fetus much like a tourniquet, preventing parts of the fetus from growing. When appendages (e.g., arms, legs, fingers, etc.) are affected by amniotic band syndrome, the constriction may lead to in utero amputations. To treat amniotic band syndrome, physicians identify the band with ultrasound and then use operative fetoscopy to enter the womb and cut the bands, thus freeing the fetus and allowing it to continue growing and developing without the hampering, dangerous bands to constrict it.

These statistics should be used as general guides when reading this book. Statistics change over time and with research organizations. The most recent statistics can be found through Internet searches or your health care provider.

To extend as much anonymity to my informants as possible, all names, including health care organizations, presented within this book are pseudonyms.

