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## Fetoscopy as Lived Experience: A Closer Look

The following short story is a composite sketch of many fetoscopy experiences. The story of Melinda and Joe is not “pure fiction”; it combines facets of many real experiences and is intended to offer a glimpse into the lives of those who create and undergo fetoscopy and to enhance your emotional purchase into a fetoscopy experience. As this book continues, many women’s stories will become fragmented. You will read parts of an experience, but never know a situation in full detail. Although I quote real women, their words reflect only small parts of their larger experiences. It is impossible to tell everyone’s story in detail; in fact, such detail would threaten the women’s anonymity. This short story offers a fuller, more comprehensive description of the fetoscopy experience without threatening individual anonymity.

Before you begin to read about fetoscopy and analyze those who create and undergo it, I ask you to imagine the following story: get to know Melinda and Joe as they come to terms (as do all fetoscopy patients) with the fact that their pregnancy is not what they expected and fetoscopy treatment may be their only option to save it.

### Melinda and Joe

Melinda and Joe are a young, upper middle-class couple in their late twenties. Joe is an only child whose family is Presbyterian, though they do not attend church or worship except for Easter and Christmas. Melinda’s mother’s family are practicing Catholics, and her stepfather is Jewish. Her mother left the Church and now attends Temple with her husband on high holidays. Melinda never knew her biological father. Her

stepfather adopted her and her older sister when they were two and four years old, respectively. Since that time, he has always been “Dad.” Melinda and Joe consider themselves agnostic and sometimes attend religious services when other family members ask the couple to join them.

Melinda and Joe attended the same university. Her major was marketing; his, business. They met their sophomore year and were married in a nondenominational, outdoor ceremony shortly after graduation. Three years into their marriage, they bought a house and decided to start a family. After nearly a year of trying to conceive, Melinda thinks she might be pregnant. They purchase a home pregnancy test and decide that they’ll test that weekend.

The following Saturday, Melinda follows the instructions on her E.P.T. kit. Together, she and Joe joke that they should be in a commercial, as they slowly watch the picture frame on the stick indicate that she is pregnant. They immediately call friends and family to announce their good news. Monday, Melinda makes an appointment with a local obstetrician to confirm what she already knows. Sure enough, she is “officially” pregnant. The obstetrician instructs her to take prenatal vitamins and watch for any signs of trouble. Melinda schedules her next few appointments and heads home.

Her pregnancy continues and she and Joe begin buying baby things and discussing names. Melinda is excited to be a “mom” and finds herself staring at strangers’ children, wondering if her child will look like him, walk like her, cry like him, laugh like her . . . Sometimes she daydreams about the sports her child will play and the piano lessons that he or she will likely hate. She’s due just before Thanksgiving, three days after her father-in-law’s birthday. If they have a son, will he be a namesake? How would her dad react to that? Maybe the baby will be a girl? That would make it easier.

The days pass, and she feels that she is getting very big, very fast. When she mentions this to friends and family, they calm her fears and tell her not to worry. Every pregnancy is different, and since this is her first pregnancy, maybe this is how her body responds.

It is her sixteenth week, and although she is becoming physically uncomfortable, she looks forward to her upcoming ultrasound. When she and Joe go to the exam she bemoans her large size. Joe smiles and

puts his arm around her, “You look beautiful,” he says aloud, then quietly whispers, “both of you.” Melinda rolls her eyes and jabs Joe in the ribs. The ultrasound technician pretends not to hear and laughingly asks, “Wouldn’t it be something if there were more than one?” Melinda and Joe laugh.

Melinda lies down on the table and the ultrasound technician begins the exam. She puts “blue gunk” on Melinda’s belly and proceeds to run the transducer over her abdomen, looking carefully at the screen. Half the time she looks at Melinda, asking her questions. How old are you? Is this your first pregnancy? Where did you go to school? What do you do? Do you have a name picked out? Do you want to know the sex? She continues searching and the conversation drops off. Her eyes squint as she dutifully makes out detail. She begins typing on the screen. Melinda asks what she is doing. The technician replies with a smile, “Well, I’m just measuring Baby A.”

Melinda asks, “What do you mean Baby A?”

The technician slowly moves the transducer to the other side of her belly, “Because this is Baby B.” Melinda and Joe search the screen trying to make out the fuzzy appearances. The technician looks at the parents. “You have twins,” she says. Melinda and Joe are stunned. They stare blankly. “No, really,” the technician says, “you have twins.”

With that, the technician continues making measurements. Melinda and Joe turn from the screen and stare at each other. Although they don’t speak, the same questions race through their heads: Twins? How did this happen? Is she sure? Is she right? Twins. Joe stammers, “Are you certain? I mean there’s no twins in our family.” Melinda nods in agreement, her body is stiff with shock and she hears the blood rushing in her head.

The technician shrugs. “It happens. You definitely have twins. There are two.” The technician tells them that she has to get the obstetrician.

The obstetrician comes in and shakes their hands. “I hear there are twins,” she grins as she sits at the ultrasound. Melinda and Joe laugh nervously.

“That’s what we hear, too,” Joe replies, still stunned. He reaches for Melinda’s hand and gently strokes her trembling fingertips.

The obstetrician takes the transducer and begins to look at the fetuses. Like the technician she, too, types on the screen as she takes fetal

measurements. She is a tall, quiet woman, wearing a white clinical coat and glasses perched on the end of her nose. Unlike the technician, she doesn't spend a lot of time talking to either Melinda or Joe. As she continues her examination Melinda and Joe begin to smile. It starts to settle in that they are parents of twins.

"What do you think?" Melinda whispers to Joe, her eyes only partly masking her concern and hope.

"Well, we wanted a family. Looks like we got one." Joe's eyes begin to fill with tears and he quickly wipes them away before the obstetrician notices.

Melinda smiles, eyes beaming, she carefully mouths, "softie." Joe shrugs, smiles and holds her hand even tighter than before.

The obstetrician continues her survey. As the minutes pass, an air of concern begins to fill the room. Melinda asks, "Is anything wrong?"

The obstetrician continues looking at the screen replying, "With twins, we just like to be certain that things are okay." She keeps clicking. "You're in your sixteenth week?" She asks.

"Yes" replies Melinda.

The obstetrician stops typing, turns from the machine and looks at Melinda. The room is silent. After a moment, the obstetrician explains, "Well, you do have twins. They appear to be identical."

"Identical twins!" Joe repeats.

"Yes, they're identical. At least it appears that way," says the obstetrician. "But there's a problem—a potential problem." Melinda and Joe look at each other. "One fetus, Baby A, is considerably larger than Baby B. You also have a large amount of amniotic fluid. I think it's possible that you have a condition called twin-to-twin transfusion syndrome." Melinda and Joe continue to look at each other. The obstetrician continues explaining. "It's a condition that affects identical twins. It's rare. What happens is there's a sharing of blood that's disproportionate between the fetuses. One bloats with excess blood and one becomes anemic. There's also an issue of increased amniotic fluid, which could lead to ruptured membranes. There are a number of problems associated with this condition. You'll want to have it looked at by a specialist. I'm going to refer you to a perinatologist."

Melinda and Joe stare at the obstetrician. It's obvious they don't know what a perinatologist is or what he or she might do for them. The obstetrician looks at them and says, "High-risk obstetrics. He specializes in high-risk obstetrics."

"High-risk?" Melinda repeats.

"Yes," says the obstetrician, gently touching her arm. "This is a high-risk pregnancy."

Melinda and Joe turn to each other as the obstetrician gets up. "I'll have my office call his office. We'll make an appointment as soon as possible. Why don't you stay here for a few minutes. Let's see if we can get through to him now. You might be lucky. He might see you this afternoon."

Melinda and Joe sit in the room alone. The faint glow of the ultrasound machine is still iridescent as the door shuts behind the physician. Neither Melinda nor Joe say a word. They sit and wait. About 15 minutes later, the physician returns. "We're in luck," she says, "he can see you today at three o'clock. Why don't you head on over?" The physician gives them the address and Melinda and Joe begin to sit up. She extends her hand to both of them. "Good luck. If you have any concerns, you can always call me, but really, you'll be better off with him."

Melinda and Joe have a few hours to spend before arriving at the perinatologist's office. They decide to go for lunch. They stare at uneaten food and begin to wonder what happened.

Finally, it's time to leave and they head to the perinatologist's office. The car ride is long and silent. Melinda finally murmurs, "I don't know what I did." Joe murmurs back, "I don't think you did anything." Melinda seems unswayed by his comments and stares out the window. Although she's lived in this town for most of her life, nothing looks familiar, it's all shrouded in a confusing haze.

They arrive at the perinatologist's office and are taken to the back room where the ultrasound machine sits besides the bed. Unlike a few hours before when she saw an ultrasound machine and her heart skipped with joy and anticipation, now seeing the machine is painful and she almost doesn't want it turned on. The reality of the situation continues to grow. What will this physician see?

She lays down on the bed and Joe sits beside her. She's told that the perinatologist will be in shortly and she waits. About 20 minutes later, the perinatologist walks through the door. He introduces himself, shakes their hands and turns on the machine. "I understand that you may have twin-to-twin," he says. Joe looks at him subtly nodding in affirmation. His eyes come to rest on his wife's naked belly.

"That's what they told us this morning," Melinda answers.

The physician begins to run what appears to be the exact same test as her obstetrician. "Yes," he says, "you have twin-to-twin. You have a pretty serious case of it, too." His words fade off as he cocks his head, peering at the screen. He continues looking and measuring.

Melinda closes her eyes. She can't look at the screen and Joe's head hangs low. The physician continues explaining what he sees. "The one fetus here, Baby A, is quite large. Baby B is smaller. Here's where the amniotic fluid is disproportionate." He continues using statistics and numbers while pointing at the screen. It's a blur at this point. Neither Melinda nor Joe really want to hear any more. He turns off the machine. They look at him.

The perinatologist sighs as he reaches for Melinda's arm, "You need to make some serious decisions, I'm sorry. There are treatment options, and of course there is termination. You can always try again."

Melinda turns to him, "What can be done? Is this treatable? Can we fix this?" After months of trying to conceive and four months of being pregnant, Melinda does not want to terminate.

"It's hard to say if it can be fixed, but there certainly are treatment options," the physician begins to explain. "Most commonly, people treat this with what we call serial amniocentesis."

Both Melinda and Joe are familiar with amniocentesis, but they're not certain why it would be serial. "What do you mean?" Joe asks.

"Well, one of the problems is the excess amniotic fluid. That's why your back hurts. That's why you're so big right now." Melinda nods. "What we'll do is we'll go in and drain off the fluid as your pregnancy continues. We'll monitor the fetuses and their development, looking for any signs of distress."

"Okay," she says, "how often does that happen?"

“It depends. It may happen once a week. It may happen multiple times a week, and of course the amount of fluid that we draw off depends on how quickly the fetuses make it.”

“Isn’t that risky?” Melinda asks.

“Well, yes, there’s always a risk associated with amniocentesis.”

“What are the other options?” Joe asks.

“Well, there’s surgery.” The perinatologist replies.

“Surgery!” Melinda exclaims.

“Yes, there’s surgery for this. What they’ll do is go in and identify the placenta—because the problem is in the placenta, you see.” He begins to sketch a picture of a placenta on the back of a prescription tablet. He continues, “They’ll make small incisions in your abdomen and enter the uterus. Then they insert lasers through the incisions and apply laser energy to the parts of the placenta where the blood is shared disproportionately. They call it fetoscopy.” As his drawing becomes more elaborate with a uterus, lasers, placenta, and stick figure fetuses, Melinda’s heart sinks. He continues, “In essence, Baby A gets his share, Baby B gets his share, and hopefully, both boys survive. At least that’s the theory.”

Melinda’s eyes begin to widen. “Well, that sounds risky, too,” she stammers. She shakes her head in disbelief. The physician’s words slowly repeat in her head. “They’re boys?” she asks.

“Yes, you didn’t know?” The perinatologist looks concerned and sorry that he let it slip.

“No, we didn’t. It doesn’t matter, I guess.” Melinda’s eyes dart between the perinatologist, Joe, and the ultrasound machine. “Isn’t surgery risky, too?”

The physician nods. “Yes, it’s surgery. All surgeries are risky. The other problem is it’s not offered a lot of places. You’ll have to travel. I can’t do it. I can do the serial amniocentesis for you, but I can’t do the surgery.”

Melinda and Joe nod. Joe asks, “Well, what are the advantages of the surgery?”

“Well again, in theory,” the physician says, “surgery takes care of the problem. If the problem is disproportionate blood flow, it might minimize or stop it.”

“What are the risks?” Melinda asks.

“Of the surgery?” The physician replies.

“No, the condition. What are the risks? What could really happen? Do we need to do anything, really?” Melinda’s eyes plead for reassurance; she is desperate to hear good news.

“Well,” the physician says, as he touches her arm, “there’s a chance that one fetus will die.” Melinda looks at him, too shocked to cry. He continues, “The problem is, if that one fetus dies, there’s also a chance that it may bleed into the surviving fetus.”

“And if that happens?” Melinda asks.

“Then they both might die, or the surviving fetus might have a higher rate of neurological impairment. It’s upwards of 25%, or so. Of course, one may die and the other may live and not have problems. It’s difficult to say what will happen, only what could happen. I’m sorry, but this is a tricky condition and we’re still trying to understand it and find ways to treat it.”

“Oh God.” She whispers. Tears begin to form in the corners of her eyes. She chokes them back, *I need to be strong. I need to listen. I need to think.* She repeats to herself. The tears dissipate and hollowness fills her stomach.

“And what about surgery?” Joe asks, “What then? What about the death rate? And the neurological issues, what about them?”

“Well,” says the physician, “there’s a chance that they’ll die, whether or not you treat them. The main difference that I can see with the surgery is that if one of the fetuses dies in utero, surgery should decrease the potential for neurological impairment of the surviving baby. It comes in closer to 5%, or so.”

Melinda turns to the physician, “Well that’s good, isn’t it?”

“Well, it depends on what types of risks you want. It depends on what you’re willing to go through. It may even depend on whether or not your insurance is willing to cover it. Another thing to consider, as I mentioned earlier, there aren’t many centers that offer this kind of treatment. You’ll have to travel. The closest center, and the one I’ve referred patients to in the past, is a four-hour flight.”

Joe’s eyes light up. “You’ve referred others? What happened?”



The physician begins to stand. “Well, one couple has two beautiful daughters. And, the other, well . . .” the physician’s tone lowers as do his eyes. After a moment he looks at Joe and simply replies, “they lost the pregnancy. They never made it to surgery. The night before the surgery, they lost it.” The physician continues to get up and head for the door, “Why don’t I let you two discuss this for awhile? Or if you’d like, go home and discuss it. If you decide to have the surgery, I’ll start making calls. If you decide to have serial amniocentesis, we’ll have to set up your first few appointments. Now, I can drain some amniotic fluid today to make you more comfortable, but if you go with surgery, I’d prefer not to and let the surgeon decide what he wants to do.”

Melinda turns to Joe. “I want the surgery,” she says, “I don’t want to wait.”

Joe turns to the physician, “Is this a very bad case?”

The physician nods, “Yes, this looks pretty bad.”

“Do you think surgery is the right choice?” Joe asks.

The physician hesitates. “I can’t tell you what I think is the right choice for you. You’re the ones who will have to live with the outcome, not me. They’re both options.”

Joe and Melinda exchange looks. “Why don’t you call the surgeon,” Joe says. Melinda nods and the perinatologist leaves. About 20 minutes later, the perinatologist returns.

“I got through to him,” he says. Melinda is dressed and they’re both sitting in the examination room, waiting to hear what to do next. “I can send your files and he’ll review them. His name is Dr. Marc Martinez.” The perinatologist hands them a piece of paper with a name and phone number. They don’t recognize the area code. “He’s been doing this for a few years now. It’s an in utero process. He’ll go in with scopes and tools and actually laser the vessels in the placenta. You’ll want to start thinking of travel plans. You may want to start making phone calls. You don’t have any children, do you?”

Melinda’s face is expressionless, “Just these” she replies, placing her hand on her belly.

“That’s good. At least you won’t have to worry about childcare. Anyhow, you’ll want to find somebody to take care of your house.

Usually people are away for three or four days, but it's best to prepare for the unexpected. If you have complications, you may need to stay longer. You know, all those things. Reserve your tickets and I'll start making phone calls on this end for your insurance." Pointing to the piece of paper, the perinatologist continues, "He wants you to call him. He can discuss your case with you. After you talk to him, you can decide if you want to go through with the surgery. If you do, please let me know. If you don't, let me know anyway, because we'll have to find a different option for you." The perinatologist leaves them and returns to his duties. Melinda and Joe head home.

Once home, they call the number that their perinatologist gave them. It's a pager. They enter their phone number, aware that it's quite late and the physician will likely return the page in the morning. They hang up and wander around the house, careful not to enter the not yet completed nursery.

Five minutes later the phone rings. Melinda answers the phone. "Hello, this is Dr. Martinez, I received a page." Melinda introduces herself and Joe picks up an extension. Martinez is somewhat familiar with their case following his discussion with their perinatologist and they discuss her pregnancy, the fetuses, and survival rates. They discuss the potential that one might bleed into the other. Like their perinatologist, Dr. Martinez is concerned. He explains that the perinatologist has mailed her ultrasounds and medical records overnight. He will know more the next morning once he has a chance to review the materials. He promises to call them after reviewing their case in detail, and in the meantime faxes them information on the condition and his surgical approach.

The next morning Melinda and Joe both call in sick to work and wait for Dr. Martinez's phone call. The phone rings and Joe answers, he waves wildly at Melinda to pick up the other extension. After exchanging some pleasantries, Martinez explains, "I'm sorry, but this is a bad case. You should be aware of it." Joe and Melinda continue listening. He explains their case in detail and answers their questions. After hearing his explanations they both agree that they want the laser surgery. There's a pause on the other end and Martinez says, "Okay, we can do that. But there's one other thing to keep in mind," he explains, "It will take you a few days to get here. We can certainly schedule surgery and I'll have my office

work on insurance. But one thing you may want to consider, if you get here and one fetus is in terrible, terrible shape, which frankly, one fetus isn't looking good right now, you may want to consider ligating."

There's silence on the other end of the phone. Melinda asks, "What do you mean ligating?"

"Well, there are two things that I can do—fetoscopically—for you. The first is what we certainly prefer, to laser the vessels. That's what your physician explained to you."

"Yes."

"The other is to ligate—to tie off the umbilical cord to the fetus that's about to die in an effort to give the other the full placenta. And also, to potentially protect it from the other fetus bleeding into it."

Melinda and Joe are completely silent. They hadn't anticipated ligation. They hadn't even heard of it. "Well," says Joe, "what about the laser?"

"Oh yes," says Martinez, "That would certainly be the first and preferable method, but it will depend on when you get here and what shape the fetuses are in at that point. We'll have to monitor the pregnancy and see what the options are once you're here. But right now, based on what I see, yes, laser is certainly an option."

Melinda and Joe thank him for his time and tell him that they'll call him back. They hang up the phone and tears begin to flow. Melinda is terrified, as is Joe. They go through the statistics. They think about their options and decide that they want the laser surgery. They call back Dr. Martinez and inform him. He tells them that it is Tuesday and he will try to schedule them for surgery on Thursday or Friday. That should give them time to get to town and go through preadmission testing at the hospital. It should also give them time to check on their insurance.

Melinda begins calling airlines. She's searching for the lowest rate possible, but doesn't have the time to call every carrier. After contacting the third one she gives up worrying about the price differences and reserves their tickets. They're slightly more than the first two airlines, but she is tired of explaining her situation to strangers and doesn't have the energy to call one back and enter another phone tree.

Together, Melinda and Joe call their parents and explain their situation. Not long after speaking with their parents, news of their condition

begins to reach other family members. Each time Melinda hangs up, it seems that another family member is calling to find out what happened. Word is quickly getting out that the pregnancy is in trouble and that Melinda and Joe will be traveling. Each time the phone hits the receiver, it begins ringing again. It's a brother; it's a sister; it's a parent; it's an in-law.

Between phone calls from confused and concerned family, the insurance agent contacts Melinda. She is uncertain as to Melinda's condition: what is it, who is the patient, and how was it diagnosed? The agent does not know if the surgery will be covered, but she will check into it. When do they plan on leaving? No, her insurance will not cover airline tickets. Melinda hangs up and her sister calls. Two hours later, and following a stream of questions from her sister, the insurance agent calls back wanting more paperwork from the physician. Melinda asks, "Who?" The agent keeps repeating that she needs a letter from Melinda's doctor. The conversation continues in circles and Melinda grows weary, "Well, is that the physician that I saw yesterday morning? Yesterday afternoon? Or the physician that I talked to a few hours ago?"

The insurance agent, also annoyed, again asks, "Which one is your physician?"

Melinda stops, thinks for a moment and says, "I don't know." She gives the agent Dr. Martinez's office and pager numbers before hanging up. The phone rings again.

And so it continues as they frantically put flights together and arrange for people to visit their house, pick up their mail, water their plants. All while hoping that the insurance company will cover the surgery.

The next day, they arrive in the city in which Dr. Martinez is located. It was a long day and they didn't sleep much the night before. Once in town, they page the doctor to inform him that they've arrived at the hotel which, thankfully, offers reduced rates to people traveling for fetal surgery. Dr. Martinez explains that he's at Holy Names Hospital and that they should come directly there for their ultrasound. They arrive for their appointment and are directed back to an ultrasound room. Another damn machine. Melinda looks at it and turns away.

At this point, she's used to laying on the table, pulling up her shirt and pushing down her trousers. The ultrasound technician walks in,

introduces herself, and says that she works with Dr. Martinez. He's on his way but she'll start the exam. Just as before, she turns on the machine and begins taking measurements. She asks them about their flight and family. She continues taking measurements. When the door opens, a middle-aged, medium-build man wearing blue surgical scrubs and a pager walks through the door. He extends his hand, "Hello, I'm Dr. Martinez. You must be Melinda. You must be Joe." They shake his hand. At least his is a familiar voice, as they had spoken with him so many times. He indicates to the ultrasound technician that he'll take over the exam. He stares at the screen, moving the transducer from one side of her abdomen to the other. He takes measurements.

He shows them the fetuses, their sizes, and conditions. He turns to them as he puts the transducer down. "Well, it's a serious case as you know." They both nod. "I think you should think about ligation, but I think laser surgery is also an option at this point." Melinda and Joe look at each other.

"We want the laser surgery," Melinda says. Dr. Martinez nods.

"Then we should do it as soon as possible." He informs them that they should come back the next day and go through preadmission testing. At that point, they'll meet his assisting nurse, Kay Brown. Also by that time, they should hear from the insurance agent as to whether or not the surgery will be covered. He asks them if they've thought about what they might do if the surgery isn't covered. Joe nods his head, "Yes," he says, "we have a new house. We might be able to refinance or take a second mortgage. I called our loan officer yesterday, she's looking into the options."

The doctor nods, a look of angst crosses his face. This isn't the first time he's heard such a reply. "Horrible," he mutters, "We'll try what we can with the insurance agent. I'll talk to them, sometimes that helps." Melinda thanks him and they leave for the hotel.

At 9:00 am the next morning, Melinda and Joe arrive at the hospital to undergo preadmission testing. A nurse takes them back into a small room where she begins to take different measurements on Melinda. Again, like everyone else, she asks, "Is this your first pregnancy? Where are you from? What do you do?" She's very pleasant, but Melinda is tired of answering the questions. Halfway through the exam, the door

opens and a woman walks through. She's tall, older, and wearing blue scrubs.

"Hi there," she says, extending her hand. "I'm Kay Brown. I work with Dr. Martinez. You must be Melinda." She walks over and shakes Melinda's hand. It's obvious that Melinda's scared. "It's okay," says Kay as she puts her arm around her newest patient, "it's all right to be scared. This should be the most exciting time of your life. You shouldn't have to be facing this." Melinda nods in agreement and begins to cry. Kay grabs some tissues on the nurse's desk and hands them to her, as she gives Melinda a hug. She turns to Joe, "You must be Joe." He nods. "How are you doing with this?" She asks, "Do you have any questions about the surgery? Can I tell either of you anything more?"

Melinda says no as she wipes her face and blows her nose. She thinks she understands, but Kay explains the surgery anyway. She explains that they'll go in with the laser, identify what they think are the vessels, and laser them in an effort to abate the condition. She hands Melinda a packet of patient materials including explanations of the surgery, informed consents, and information on the hospital and surgery program.

As a seasoned fetoscopy nurse, Kay has a very calming way with Melinda and Joe, and they seem a bit more relaxed now that she's there. They begin to ask about other patients. Have other people been scared? How long have other people had to make their decisions? Kay acknowledges that most people make their decisions quickly. The issue is trying to catch the condition before it gets too bad, "Before we lose the fetuses," she says. "We don't like losing babies." They agree.

"Do you want to talk to one of our chaplains or a social worker?" Kay asks. "We've got some great chaplains here. Our social workers are very nice, too."

Melinda and Joe indicate that they would rather not talk to anyone else. At least not a chaplain or a social worker. Kay says, "Okay, but just know they're here, and they'll be happy to talk to you if you want to talk to them. Have you met Deb?" she asks. Joe looks at her. "Who's that?"

"She's a social scientist working on her Ph.D. She's been here for most of the year. She's studying how this works and who we are, you know,

kind of anthropologically.” Kay laughs a bit as she waves her hand aimlessly through the air alluding to the variety of questions and activities that have become associated with Deb’s project.

“No, we haven’t met her,” Joe replies.

“I’ll introduce you,” Kay says. “Do you have any other questions for me?”

“No, no other questions.”

“All right,” says Kay, “I’ll leave you to finish here, then I’ll see you tomorrow. When you come in for surgery, you’ll come back to this same desk. And if you have any questions at that point, we can answer them then.”

“Okay,” replies Melinda.

“In the meantime, you take that packet back to the hotel, look it over very carefully, and if you have any questions—any questions at all—either page me this afternoon or write them down and bring them with you.” She hands them her pager number.

“Okay,” they agree, and Kay leaves.

A short while later, Kay returns with another woman. This woman is younger, maybe in her late twenties, and not wearing scrubs. “This is Deb,” Kay says, “Deb, this is Melinda and Joe. I told them a little bit about you, but why don’t you explain it. In the meantime, I’ll see you two tomorrow.”

Kay leaves and Deb introduces herself and her project. She explains that she’s working on an interdisciplinary degree in social science. She interviews patients and their companions, and sometimes observes surgery. She also interviews physicians, social workers—anyone who has a hand in building fetoscopy experiences. She gives them her own packet of information explaining that she would like to interview them about their experience and if they’re willing, to observe Melinda’s surgery. Deb asks them to think about it, and not to feel pressure to consent or not to consent to being involved in her project. She explains that her study is separate from the fetoscopy surgery and that regardless of their choice, she wishes them well. After asking if they have any questions about her work she leaves them for some time to discuss it privately.

When she returns, Melinda and Joe sign their consents and both seem intrigued by the prospect of being interviewed and sharing their story.

Melinda smiles and explains that she's very willing to be interviewed, especially if she can complain about insurance issues. She still does not know if her surgery will be covered. Deb thanks them and tells them that she'll be there the next morning.

Morning arrives and Melinda and Joe return to the hospital. Kay and Deb meet them in a back room to discuss Melinda's surgery. Deb leaves and Kay continues to sit with them, making certain that they have all their medical questions answered. When they're called into the preoperative area, Melinda leaves and Joe stays behind. Melinda is instructed to put on a surgical gown. It is flimsy and she's not certain which is the front and which is the back. After adjusting it in different ways in hopes of trying to cover most of her body, she makes her way to the gurney that's been set aside for her. She lays down on the gurney and soon preoperative nurses surround her, asking her a variety of medical questions and then asking them again.

Joe is called to the back room and stands at the side of the gurney. One by one, people from the fetoscopy team come back to meet Melinda. They ask her the same set of questions, and she answers them. A little while later, another woman in scrubs comes to meet Melinda. She introduces herself as the nurse anesthetist who will be taking care of her. She has a pleasant face, is middle-aged, and has a distinct accent that Melinda cannot place. She speaks in soothing, almost motherly tones.

"Don't worry, honey, I'm the one who's going to take care of you," says the nurse. "I'll be right there through the whole thing from when you go to sleep to when you wake up, I'll be right there. Have you ever had general anesthesia before?" she asks.

Melinda says no and confides that she still has her tonsils. She had her wisdom teeth pulled, but they used Novocain.

"Well, do you have any concerns about anesthesia?" the nurse asks Melinda.

Melinda replies, "Well, yes, I'm scared. I've never had it. I will wake up, right?"

The nurse smiles. As she begins to reassure Melinda, Joe speaks up. "What about this thing about people feeling pain during surgery? I saw it on the news a few months ago. Will she feel anything?"



The anesthetist shakes her head and makes a face of disgust. “They just scare people. It’s awful,” she says.

“Well,” says Joe, “it scares me.”

The nurse anesthetist nods. “Those are very rare cases. But, in fact, yes it does happen that people have bad experiences and some people do die or suffer effects from anesthesia, or surgery in general. But like I said, that’s a very rare situation. The chances of it happening to you are very small. I’ve never had anyone tell me that they’ve felt or remembered anything. But there are risks with surgery—to both you and the babies. You need to remember that. There are risks, here.”

They continue talking and discussing the risks of surgery and anesthesia. Melinda thanks her for taking her concerns seriously and tells her that she doesn’t have any more questions. After asking her the same questions that everyone else has asked, the anesthetist rubs Melinda’s arm, grins widely and says, “Well, I’ll see you in surgery.” She shakes Joe’s hand and leaves.

Throughout the morning, people come back to see Melinda. Kay comes to make certain that Melinda is comfortable. Dr. Martinez comes and makes certain that the informed consents are filed and to answer any lingering questions about the procedure, their goals, and its risks.

Later in the morning, Deb appears around the corner of the screen. She looks different now that she’s wearing blue scrubs and seems to look more like the medical team than the person they met the day before. Deb walks up and touches Melinda’s arm. A faint smile is all she can offer and a soft, “hi, Melinda.”

Melinda smiles a bit, “Look at you,” she quips. Everybody looks the same in the blue scrubs, almost like a uniform.

“Yes, very stylish, don’t you think?” Deb replies.

“Well it’s more than they gave me,” says Melinda, looking down at her surgical gown.

Deb nods in agreement while continuing, “I just wanted to check in and wish you well and ask if there’s anything that I can do for you.”

Melinda replies, “No, no. There’s nothing. I’m just waiting to be taken back.”

Deb turns to Joe who shrugs and nervously laughs, “Pray?” His pained eyes betray his forced laugh.

“Pray?” Deb asks, a bit surprised, but moved by the honest request. She responds quietly, “Okay, I can do that.” They both look at her as she continues, “I can, if it would help. If you want me to, I will.”

They both look at her and kind of nod. “It can’t hurt,” Melinda says as she quietly rocks Joe’s hand in her own.

“No, I imagine not,” Deb replies, “after all, I’ll just be there with a notebook, taking notes. I don’t handle any tools. I can do that much for you.”

Joe seems relieved. Melinda seems less concerned, but thanks Deb just the same.

“Okay, is there anything you would like me to say in particular?” Deb asks, not knowing their religion or spirituality.

“No, I don’t think so . . .” Melinda responds while turning to Joe, “I don’t know any prayers, really.” Joe nods in agreement, then adds, “Just ask God for help.”

“Okay. I’ll just say a quick something right before they start, how about that?” They both thank her and she leaves.

More people continue visiting with her, asking if there’s anything they can do to help her. Finally, Kay shows again. She asks Melinda how she’s doing. They’re nearly ready in surgery. Melinda says she’s okay, but then looks off in the distance. Leaning down toward the gurney Kay gently asks her, “What’s the matter? What is it? Is there anything that we can do?”

“It’s just,” she says beginning to choke up, “It’s just, I mean, I’m going to go to sleep and when I wake up, my babies might be dead.” Joe’s head drops, while tears begin to roll down Melinda’s face. Turning away, Joe silently wipes his eyes. Reaching through dangling wires and flashing monitors, Kay gives her a hug explaining, “We’ll do everything we can to make certain that doesn’t happen,” then she pauses and continues, “but it might.”

Melinda nods, “I know.”

At that point, the nurse anesthetist arrives, indicating that they’re ready in surgery. “Are you ready?” asks Kay.

“Yes” says Melinda. Joe nods as well. He kisses his wife; they take her away.

Melinda watches the ceiling whirl by as they wheel her to the operating room. Fluorescent lights pass in a dizzying effect. Then, as suddenly

as it started, the gurney begins to slow. She knows she is coming nearer the operating room. She begins to see people, their faces are obscured by surgical caps and masks, but at least some of the eyes seem somewhat familiar.

“Remember me?” asks one set of eyes, “I’m Christine, I did your ultrasound yesterday. I’ll be doing it today, too,” she says as she reaches out to touch Melinda’s arm. The gurney makes a tight turn and Melinda is in the operating room. At this point she wonders how far she’s gone and where Joe might be. They transfer her onto the surgical bed. There, she sees the nurse anesthetist who begins to brush Melinda’s hair away from her forehead.

“Hi there, sweetie pie,” she says, “everything’s going to be fine. I’m just going to get some medications going.” The nurse anesthetist nods to Kay who heads out into the hallway, asking if anyone has seen Dr. Martinez. He’s standing in the hall, discussing the case with some of the nurses. He’s outlining his approach by doodling on empty supply cartons.

“We’re ready,” she says.

“Good.” He walks into the surgery and stands beside Melinda. “How are you?” he asks.

“Fine,” she says. He rubs her shoulder closest to him and begins to hum. “You’ve met everyone?” he asks.

“Yes, I think so.”

“Good. Well, if you’re ready, we’ll go ahead and put you to sleep. Then we’ll start surgery.”

Melinda says that she’s ready and Dr. Martinez continues to stand there, rubbing her shoulder and humming a song that Melinda vaguely recognizes. The nurse anesthetist slowly begins to put medications into the IV and Melinda drifts off to sleep.

The doctor returns to the hall. He begins the process of scrubbing, as do the nurses, the ultrasound technician, and his assisting physician. Meanwhile, the nurses left in the operating room begin to remove the sheets that cover Melinda. They clean her abdomen and drape her with blue surgical cloths.

Once she is ready, Dr. Martinez and the rest of the team enter the room. To one side of Melinda’s body stands the doctor and a nurse who

will hand him tools. On the other side is an assisting physician, one of the doctor's partners, and the technician who will run the ultrasound throughout the surgery. Also in the room is a nurse running "the tower," a complicated, mass of machines through which she can switch between fetoscopy video and ultrasound images. Others in the room include Deb, who's standing in the back corner, another nurse who will work the laser machine, and a final nurse, the circulator, Kay, who will troubleshoot the case if anyone needs help. The room is small and compact, but not uncomfortably tight.

Surgery begins. Dr. Martinez has the lights dimmed. The only lights remaining are those emanating off the machines and handheld flashlights. He makes a small incision in Melinda's abdomen and pushes in the trocar, a small funnel-like instrument. He does this through ultrasound guidance, careful not to rupture any amniotic membranes. Watching for bleeding, he then inserts the tools, through the trocar. Once the scope is inside, he looks around and sees the placenta. He slowly begins the process of identifying the different parts of the placenta, trying to see which vessels he will need to separate. After identifying them, he asks the nurse operating the laser to start the machine. He inserts the laser and gently applies energy to the vessels, theoretically separating the blood flows. Once he has lasered the placenta in the areas that he thinks are necessary, and the assisting physician agrees that they have accomplished their goal, they begin to remove the tools from the uterus. At that point, a fetal hand is cast into view.

A nurse cries out, "Oh that one! Take that shot! Take that picture for the parents!" The doctor complies and dutifully pushes the button on the camera to take a still photo of a fetal hand.

"Okay," he says, "we're outta here on three. One—two—three." On the third count, he swiftly removes the trocar and watches for bleeding on the ultrasound. There doesn't appear to be any. The trocar came out just as swiftly as it went in. The membranes seem to seal behind it. It was a successful case, technically.

"What was the time?" the doctor asks as he steps away from the gurney and Melinda.

"Two hours and twenty minutes," replies one of the nurses as she continues to take down information on her clipboard.

“Good, good . . .” he responds as he begins to remove his surgical gloves. He leaves to find Joe and explain the case. When he enters the waiting room, the nervous father immediately stands. He tries in vain to read the doctor’s face, but it offers little insight. As the doctor walks to Joe, he extends his hand and says, “Well, mom’s okay and the babies are okay.” Joe sighs, shakes his hand, and a smile begins to appear. The doctor motions toward two empty chairs and they sit. He explains the case in detail and Joe nods his understandings. “But,” he continues, “You need to remember that your babies are very sick. I’ve done what I can—but you’re not out of the woods. We’ll have to watch the pregnancy and see how the babies respond, okay?”

Joe replies, “Okay, I understand. Cautious optimism, huh?”

Dr. Martinez laughs and begins to stand. In response, Joe stands. “Yes, cautious optimism” the doctor repeats as he shakes Joe’s hand and pats his shoulder. “Recovery will call you when she wakes up. I’m going to check on her now.” He leaves and Joe sits down.

Back in the operating room, the remaining nurses remove Melinda’s drape and wash her abdomen and put Band-Aids over the insertion points. The nurse anesthetist slowly begins to rouse Melinda. Rubbing her cheeks, she repeats, “Wake up, honey. Wake up. Surgery’s over. The babies are fine. Wake up, wake up.”

Melinda begins to awaken as a transport gurney arrives. Kay, the nurse anesthetist, and the recovery room nurse wheel Melinda down the hallway as she lays back, groggily watching the same fluorescent lights that she had seen only hours before. Her throat is sore from being intubated, but she closes her eyes when she hears that everything is fine. She feels nauseous. Very nauseous.

A recovery room nurse straps a fetal monitor on Melinda and verifies that there are two fetal heartbeats, but one is weak. Kay comes around to Melinda’s side, rubs her shoulder and tells her that her surgery’s over, repeating the same words that the nurse anesthetist did. “We’ve got two heartbeats,” she whispers, “you rest, soon we’ll bring back Joe.”

“Sick . . .” Melinda whispers.

“You feel sick?” Kay responds, lowering her face so that it’s inches away from Melinda’s half-opened eyes.

“Throw up . . .” Melinda continues to choke out mumbled warnings that she may vomit. Kay steps away to let the nurse anesthetist talk to Melinda.

“Hi, sweetie,” she says, as she gently caresses Melinda’s pale and slightly contorted face. After years of rousing patients, she finds that nothing is more soothing than human touch. She continues to softly push Melinda’s hair back. Melinda is clearly suffering the effects of the drugs used to control her ensuing contractions. She had been warned that contractions might follow the surgery but that they were generally easily combated with proper medication. But this medication—this was too much. Melinda was not prepared.

“. . . going to be . . . sick . . .” Melinda repeats.

“It’s okay. You’re okay. These are the drugs to help you keep the babies. We’ll take you off of them as soon as it’s safe.”

“Throw up . . .” she repeats. Kay hands the nurse anesthetist a pan, should Melinda begin vomiting.

The nurse anesthetist continues to soothe Melinda by promising her that she’ll take care of her. “It’s okay, there’s nothing there to vomit. You may have dry heaves, but you won’t choke. I won’t let that happen to you. You’ll feel like you have the flu until we can get you off these drugs, okay? Try and get through it, sweetie. I know it’s awful.” The nurse anesthetist continues stroking Melinda’s hair while Kay begins to rub her lower legs—anything to assure her that she’s not alone. Melinda closes her eyes. She has never felt this sick. The nurses fade to the background as Melinda concentrates on her babies. She groggily vacillates between fearing for her babies’ health and her own.

Dr. Martinez returns to Melinda. She still feels sick, but is aware of her surroundings. She nods and mumbles responses. Like the nurse anesthetist and Kay, he assures her that there are two heartbeats, for the moment. He describes the surgery and explains that he’s still worried because the fetuses are in bad shape. Joe knows that she’s in recovery and when she awakens more, he’ll be brought back. After that, they’ll take her to labor and delivery and continue to control the contractions. Melinda whispers a thank you and the doctor soothingly rubs her arm. Unable to accept the thanks of a desperate mother he

simply smiles his acknowledgment and responds, "I'll check on you later." He leaves.

Eventually, Joe arrives and he and Melinda are transferred to labor and delivery. All night long, Melinda is given drugs to keep her contractions under control. She's absolutely miserable and terribly thirsty. Joe sits back in a recliner and worries. Occasionally he wipes the hair from her face and runs an ice cube over her lips. His thoughts flash back to his grandmother's battle with cancer and ineffective chemotherapy. The nurses check on her and Dr. Martinez returns quite late at night to check on her as well.

The following morning her contractions have subsided and they take her off of the drugs. She is transferred to high-risk obstetrics where she finally stomachs some food. Kay returns to check in on her. This is the third time they've seen her since the surgery.

"Don't you have other patients?" Melinda jokes as the presence of Kay is consoling. Joe also finds comfort in her visits.

"Oh yes, that." Smiles Kay. "Of course, but I like to take extra special care of my extra special babies." She checks Melinda's vital signs and sits beside the bed, where the three of them discuss the surgery and their hopes for the future. After a half an hour of visiting Kay admits that she has to get back to work before she is missed. She leaves but promises to return before her shift is over.

After Kay's visit, Melinda continues lying in bed. An hour later, Dr. Martinez arrives to run a "bedside" sonogram. The sonogram is wheeled into the room and he watches the pregnancy. He shakes his head a bit and gives them the bad news. Unfortunately, it doesn't look like the surgery helped much. The one is still in bad shape and doesn't seem to be getting better. The other is holding his own. He tells them that he'll continue to watch them throughout the day and look for possible signs of change. He lists the different signs that the pregnancy is improving and assures Melinda that they'll watch for them. Melinda and Joe wait.

Throughout the day, sonograms are ordered and they watch.

The following morning, they run another sonogram. The doctor tells them that one fetus is quite ill and likely will not survive. They should

consider ligating. He speaks with Joe and Melinda about the procedure and leaves them to decide.

It's a long morning. Melinda immediately wants to ligate. Joe is hesitant. He can't understand her reaction and asks her how it is that she could kill their baby? Why would she want to kill him after all that they've been through? Melinda looks at him and explains that she's not killing a baby, she's saving a baby. They continue to debate, knowing that time is ticking away. If they want to ligate, they're going to have to decide soon.

Neither one of them is happy with the choices offered and the prospect of making a decision is very, very painful. It's clear that they can't agree. "If we ligate," Joe asks "What then? What are we supposed to tell his brother when he gets older? How are we supposed to tell him what we did?"

Melinda shakes her head. "It's not that we've done something. It's that we can't do anything else."

Joe looks down. "How do you think he'll react to that? Knowing that Mom and Dad, you know, tied off his brother?"

Melinda looks down at her stomach. "I think it depends on how we tell him. Maybe it depends on if we tell him."

Joe looks at her. "What do you mean, if we tell him?"

"Well, maybe we're not supposed to have twins? I mean we only planned on one, and maybe I'm only supposed to have one?" Melinda looks at Joe, she's confused and straining to make sense of the situation.

Joe shakes his head. "You mean, he'd be the only person in the family not to know that he had a brother?" Joe sighs and shakes his head, "No, we can't do that."

Melinda continues, "I'm not worried about him blaming us, I guess. I'm more worried that . . ." she stops in mid-sentence, staring out the window.

"What?" asks Joe. "What's worse than blaming us?"

"I'm worried that he'll blame himself."

"What?" he asks.

"I'm just worried that he'll think that he stole his brother's blood, his food, his air . . . that he killed his brother. I couldn't bear that. I'd rather he think that we killed his brother than he did."



Joe shakes his head. “I don’t want anybody to kill anybody. I just want my babies.”

Melinda begins to cry. “Don’t you think that’s what I want, too?”

They continue to discuss what death means, what killing means, when life begins, when life doesn’t begin, how life should end, how life has to end. For hours, they talk, cry, and debate. They ask to see the chaplain and they ask to see social workers. They debate calling their parents and decide not to call. The decision’s too hard for them, let alone their parents.

Later that afternoon, Joe and Melinda decide to ligate. Comparing their decision to turning off life support to a dying family member, they tell Dr. Martinez that they want the ligation as soon as possible. The doctor explains that they’ll have to convene an ethics committee meeting in which he’ll explain the case. He assures them that this is nothing new. All ligation cases must be reviewed before the committee, but he feels this is a clear-cut case and ligation is medically warranted. Nevertheless, there is always the potential that the committee may reject it. They’ll know the next morning.

The following day the ethics committee meets and Dr. Martinez explains the case to a small group gathered around a table. He answers their questions and by the end of the meeting, they are in agreement. Ligation is warranted. He goes upstairs to tell Melinda and Joe that their case was accepted. It passed. They can do the ligation, if they still want it.

Joe and Melinda agree that yes, they still want it, but Melinda is a bit hesitant. “What’s going to happen?” she asks. The doctor looks at her.

“Well, we’ll take you back to surgery just like before—” he begins to explain the surgery.

“No,” she says, “what’s going to happen to my baby? What’s going to happen to the dead baby?”

He explains that without blood and nutrition, it will begin to emaciate. It won’t hurt the surviving baby, but it will remain inside.

Melinda looks panicked and somewhat horrified. “You mean the dead baby’s going to be with the living baby for the rest of the pregnancy?”

“Yes.”

“Inside me?”

“Yes, it will remain in utero.”

“And when I give birth? What then?” Melinda asks, her eyes widening.

“You’ll give birth to both,” Dr. Martinez says.

“And what do I do with the dead baby?” She asks.

“Well,” he explains, “you can cremate it, you can bury it. You can do any number of things. You can see it. You don’t have to see it. You’ll want to work that out with the department of social services at your delivery hospital.”

Melinda agrees. As she signs the papers consenting to ligation she mumbles, “I’ll be a walking graveyard.” Joe reaches for his wife and the doctor stands silently.

Later that afternoon she is taken back to surgery and the same processes ensue, only this time she knows that she’ll go in with two heartbeats and leave with one. She’s wheeled down the corridor and the fluorescent lights pass by. She’s taken in and as before, the lights are dimmed and surgery begins. This time, however, the placenta isn’t the object that the doctor searches for, but the umbilical cord leading to the dying fetus. With miniaturized sutures, he ties it off and everybody in the room waits to make certain that the blood flow ceases. A few minutes pass. It is dead.

At the end of the surgery, Dr. Martinez again counts to three and removes his scopes and trocar, announcing “We’re outta here.” He steps away from the table and tells the rest of the team that he’s going to talk to Joe. The nurse anesthetist begins to rouse Melinda. Like before, she rubs her face and her shoulders. She removes the intubation and careful not to mention the babies, she gently whispers, “Wake up, sweetie pie. Wake up, honey. Melinda, case is over. Everything’s fine.”

The following two days are similar to the first days when they arrived and underwent laser surgery. She’s taken to recovery and labor and delivery. Again, she suffers through the powerful drugs to control her contractions. Ultimately, she returns to the high-risk obstetrics floor to be monitored. Here they run ultrasound exams throughout the day to make certain that the surviving fetus remains a surviving fetus. The ultrasounds are painful to watch as Melinda sees her one live baby, and occasionally catches glimpses of the other. The dead baby doesn’t move. She finds

watching the ultrasound too painful and can't watch them any longer. She hopes within a few days or possibly weeks, to return to watching them, but it will take time.

The next day, Dr. Martinez tells them that the case looks good, that the fetus looks fine. They can return home under the care of their other perinatologist, who will see them through the end of their pregnancy. They thank him for his efforts and he leaves the room. Throughout the day, nurses come in and offer condolences for the decisions they had to make, and best wishes for the future that lies ahead.

Deb comes in and interviews them. They explain the pain of making their decisions. They explain their fears and hopes. Like other interviews, this one is at once painful and hopeful. The three of them sit around the room talking about the case and the decisions. They still don't know what they may or may not tell their baby. They're filled with many questions. They don't know what they'll do with their dead baby. They think they may cremate him and take his ashes home. But they also want to be able to "move on" as Melinda explains. Maybe she won't take the ashes home. They're not certain, but they have time to make that decision. They'll probably talk to their parents.

Deb wishes them the best for their pregnancy, and as with the nurses, offers her condolences for the son that they lost. They thank her. She asks when they're leaving and they tell her later that night. They have a flight booked and are looking forward to going home and being in familiar surroundings.

Later in the day, they are released from the hospital and many of the people who cared for them come by to say good-bye. They exchange emails with Kay and phone numbers. They promise that they'll let her know when the baby arrives. After seven days, two surgeries, and the death of a son, they leave and head home.

While home, they continue monitoring their pregnancy with multiple ultrasounds and visits to the perinatologist. As they prepare to make room for a new baby, they also prepare to make room for a dead baby. They speak with mortuaries and decide what they want done with their dead baby. They opt for cremation and will bring the ashes home. Hopefully, they'll spread them somewhere, maybe by a tree, but not until they know where they're going to eventually settle. They're not convinced that

they're going to stay in this town forever and they don't want to leave their dead baby behind. Friends say they sound morbid discussing these things, but they shrug. What else can they do?

A month or so before her due date, Melinda goes into labor. She's taken to a local hospital where she delivers both babies vaginally. One is pink and crying. He's small, but very much alive. The other is smaller, still babylike, somewhat emaciated, and a deep purple. She holds both. She names both. One is taken to the nursery; the other to the morgue.