

An Error in Cell Division, or The Power of Positive Diagnosis



When we walked into the doctor's office, both my husband and I were crying. He looked up and said, "What's wrong? Why are you both in tears?" "It's our baby. Our baby is going to die," I said. "That isn't a baby," he said firmly. "It's a collection of cells that made a mistake." (Leah Rubinstein, 39, white homemaker)

THE SHOCK OF RECEIVING BAD NEWS is never routine, no matter how ordinary its contents may be for the diagnostic laboratory. The discovery of an extra number 21 chromosome in fetal cells on a slide produces the cytogenetic technicians' most common positive diagnosis of Down syndrome. But every woman with whom I have spoken recalls the delivery of this, and every other diagnosis, vividly. The receipt of a diagnosis shatters the routine of daily life:

In my mind the tape repeats endlessly. I can hear the genetic counselor saying it again and again, "I'm sorry, Adrian, I'm calling with some bad news. Are you alone? Would you like to get your husband to the phone?" (Adrian Miller, 39, white medical science writer)

Everything slowed way down. I don't get hysterical, I get methodical; under stress I just, you know, get very quiet. I asked him, "How sure are you? What are the odds? Do we need to repeat this test?" I didn't flip out until I found myself in the car, going to pick up my husband, sobbing on the highway. (Margaret Thompson, 34, white psychologist)

When bad news arrives from the cytogenetics lab, it is usually delivered in pieces. Many women told stories of being called by genetic counselors, or by obstetricians, who would not divulge the exact nature of the problem over the telephone; they preferred for the pregnant woman (or, ideally, the couple) to learn the relevant details in person. Many women also complained about this protocol; while acknowledging the competence, and often, compassion, of the counselors, they would have preferred to have the diagnosis named on the phone, rather than ruminating while waiting for an emergency appointment, often a full day away. Some counselors and doctors do, of course, "tell all" in the first conversation. While some women found this to be a relief, others had the opposite reaction. Of the fifty women receiving positive diagnoses whom I interviewed, at least two complained about the insensitivity of having counselors call and "blurt out" such deeply disruptive news: They would have preferred to hear it more gently from a private obstetrician with whom they had an ongoing relationship. The obvious point of these different stories is easy to spot: There is no good way to get bad news. And the circumstances of its delivery are indelibly etched into the memory of everyone with whom I spoke.

These circumstances are particularly dramatic when they entail a diagnosis made by ultrasound, rather than through chromosome studies.⁴¹ Visualizations are presented on a monitor quite similar to the ubiquitous television screen, and their impact is instantaneous. They hold a powerful place in women's narratives, and are recalled far more vividly than the "caterpillar stick figures" of karyotype photographs (cf. Drugan, Greb et al. 1990). In the cases where spina bifida, anencephaly, or life-threatening heart, lung, and kidney problems were visualized, women from diverse sociocultural backgrounds seen at the full range of New York's hospitals told virtually the same story:

Pretty soon, it was a regular doctors' convention in there. At some point, I must have had eight doctors muttering over that screen. I said to myself, my God, something is terribly wrong here, because they keep calling other people to come in and take a look. I know they wanted their opinions. But they wouldn't say anything to me. (Marilyn de Soto, 34, Puerto Rican social worker)

He just kept looking and looking, and the area that I noticed that they looked at most basically was the heart. They just kept focusing on that. The technician called the doctor, the doctor called more doctors.

I asked, I kept saying, over and over, "What's the problem?" Because I told my husband, I says, "With Leona, I was in and out in half an hour, this is all wrong." I kept asking the technician, but you know, they don't tell you anything, because they're not really allowed to. . . . Finally, when the doctor came in, I begged and begged, and she said, "Well, we're noticing a little fluid in one of the baby's lungs." And I said, "What can that be from?" And she said, "We really don't know at this point. We're going to go ahead with the amnio, and when you get upstairs, you just tell your counselor, and she'll talk to you." When she told me that, I knew at that point that she already knew. She just didn't want to be the one to tell me. (Nivia Hostos, 26, Puerto Rican administrative secretary)

Then when the radiologist came in she called the other one, the clinician, and they started looking more and more, and focusing on more and more places. Not that I knew what was going on, but I knew that it looked ominous. You could feel something hanging in the air in there. And suddenly there were more and more people in the room, and they're changing positions around the screen, and they're highly focused, but they never talk to you. Then, they turned off the machine, and they all left the room. And they sent me out of the room without telling me what they had seen. (Tamara Levkovitz, 34, white private school teacher)

Sometimes, women intervene in hospital protocol, attempting to gain access to information which they desperately need. Marilyn de Soto, for example, opened the sealed envelope containing the ultrasound report while waiting to deliver it to the genetic counselor. "It's my body, I have a right to know," she told me. She thus read the diagnosis of fetal polycystic nephrosis—a fatal kidney condition in this case associated with the diagnosis of trisomy 13. Later, crisis-racked, with her veterinarian husband at her side explaining the second sonogram, she "saw for herself": "I'll never forget seeing the black hole where the kidney should have been. And a lot of damage to the other one. That's something that you could see. That's what did it for me."

Forced Choices

The delivery of a positive diagnosis inevitably forces the pregnant woman and her supporters to make a decision to continue or end the pregnancy. The full impact of that decision-making process is, of course, multifaceted and com-

plex; it provides the subject of this chapter. But one of the first things that struck me when I began interviewing women who had been through this painful process was that my sample divided dramatically into two groups: those who more or less knew that they would choose abortion if a serious condition were diagnosed in their fetuses, and who therefore "decided" instantaneously upon hearing bad news; and those who needed to work their way through the problem step-by-step, arriving at the abortion decision as the conclusion of a more protracted process. The two strategies condense multiple differences, including the very significant difference between understanding common and arcane or ambiguous diagnoses, discussed below. But in addition they reflect sociocultural influences on women's comfort and trust in biomedicine, including diagnostic technology, and the prior knowledge, attitudes, and beliefs that pregnant women and their supporters hold about specific disabling conditions, as well as about childhood disability in general.

The use of abortion after a serious positive diagnosis seems almost automatic, if nonetheless painful for some women, especially under two conditions. One is the diagnosis of Down syndrome, with which they feel familiar. This diagnosis is the single most common one made through amniocentesis, and accounts for almost half the chromosome problems detected. While there are no national figures for abortion rates following positive diagnosis, epidemiological and biostatistical experts estimate that more than 90 percent of women receiving this diagnosis go on to abort (Drugan, Greb et al. 1990; Hsu 1989). One Midwestern study found that 93 percent of the women receiving what the physicians characterized as "severe" prognoses, including all autosomal (nonsex chromosome) trisomies, of which Down's is the most common, decided to abort (Drugan, Greb et al. 1990). These suggestive studies correlate well with data collected in England, where national statistics on abortion following a positive prenatal diagnosis are kept. There, 92 percent of those receiving this diagnosis chose to end their pregnancies (Alberman, Mutton et al. 1995). The second factor which seems to influence an "automatic pilot" response to a serious diagnosis is attachment to an upper-middle-class, or middle-class, Jewish background:

Decision, what decision? It comes with the territory. If you're having amniocentesis, you're having an abortion when they find something wrong. (Leah Rubinstein, 39, white homemaker)

We talked it over before deciding to have amnio. If I was going to have it, we would already know that I was going to have the abortion. People always have their opinion, and people were saying, "If it's Down

syndrome, you don't want to have to live with that for the rest of your life." I can tell you a lot of compassionate stories about friends with mentally retarded kids. And I know if we just had a kid with that problem, with no testing, we'd do the right thing, we'd love that child and raise it well. But the bottom line is, we agreed that we want to avoid this problem if we can. (Fran Goodman, 34, white nonprofit community service worker)

And, of course, while virtually every Jewish woman in my sample had this response, they were not alone. Many others also told stories in which decision-making was instantaneous, almost always with Down syndrome, and sometimes, with other conditions, as well:

And when the doctor told me, that was the first instance when I knew that I was going to have an abortion. I made up my mind instantly, I checked in the hospital right away. . . . It was the only thing I could have done. I mean, it was the only thing I could have done. (Nancy Tucker, 36, white college professor)

An unambiguous decision does not entail less suffering:

Sure, it was the best decision I could have made under the circumstances. It was a perfectly right, clear decision, but an enormously painful one. (Diana Morel, 28, Puerto Rican secretary)

I feel fine about the decision, I'm fine with it. Nothing could have been more obvious. It's just that my heart is permanently broken. (Donna deAngelo, 38, white homemaker)

Most of my respondents had prior knowledge about Down syndrome gleaned from neighbors, friends, and kin who had children with this, or another, form of mental retardation. Seven were teachers or social workers whose professional life had brought them into contact with families with disabled (usually, mentally retarded) members. Sylvia Lin, 43, Japanese-American special-education teacher, said, "I told my husband, 'Down's, that means practically nothing.' Because I've seen them very retarded, and I've seen them practically normal."

Other women also had more nuanced understandings of this, and other disabilities:

I knew enough to know not to worry about Down's babies. They're cute, they get by. But you really worry about what happens when they grow up, when you get old, when you die. Who takes care of Down's babies then? (Harriet Genzer, 41, white editor)

I had an autistic brother. My mother put everything she had into him; it ate up her whole life. Maybe the kid would do well. But what about me? (Megan Johnson, 41, white writer)

And some expressed self-criticism of their own aversion to keeping a child with the diagnosed disability:

I'm not proud of this, but to be honest, I don't want to cope with a mentally retarded child. My mother did volunteer work in the schools, with MR kids. She's deeply against abortion. But she's not against abortion for this. I guess some of her attitudes must have rubbed off on me. The thing that entrances me is having a smart child. (Sally Hart, 38, white college professor)

The Chosen Loss

Knowing (or thinking one knows) about a condition undoubtedly strengthens the resolve of decision-making. But it doesn't lessen the pain of loss. Ending a wanted pregnancy is a multifaceted, complex process which all the women with whom I spoke consistently identified as a profound loss. The emotional recovery after what is medically labeled a "selective abortion" is lengthy. Women and their supporters experiencing this process share an existential territory with all who survive the death of loved ones; they also have much in common with those recovering from any pregnancy loss or stillbirth. But their experience is also distinct because it is a chosen loss (Black 1994; Kolker and Burke 1994). The idea of "choice" is one to which women returned again and again, especially highly educated, middle-class women. Said Pat Gordon, a 37-year-old white college professor, "I felt like a voice in a Greek chorus, chanting, 'Your choice, your choice, your choice is upon your shoulders.' I felt like a minor figure in a major tragedy."

Yet for some, the very notion of "choice" is unbearable and must be abolished from the vocabulary of grief. When I asked about decision-making, I heard again and again, from women of diverse backgrounds, "I had to have an abortion" or "It was a forced choice." Some were even more explicit:

I'd prefer the doctor told me the baby was dead. I kept secretly hoping it would die before we got to the hospital. Then I wouldn't be part of causing this loss. (Nivia Hostos, 26, Puerto Rican administrative secretary)

Don't speak of it as an abortion, that's disgusting. This was a loss. I did what I had to do, I couldn't help myself. It's a loss, not an . . . (Harriet Genzer, 41, white editor)

Others acknowledged their ambivalence about what one woman who identified herself as "a rabid pro-choicer" nonetheless called "being an accomplice to a murder." And some spoke of the pain in having to have a choice at all:

When I was going to Dr. R's office to have the laminaria put in again and again, I kept thinking: No one is forcing me to do this. I'm making my own choice. This is awful. It's the single most awful thing that's ever happened to me. But it's my choice, and I'm making it. (Michelle Kansky, 38, white public school teacher)

Indeed, the seriousness of "choice" was a theme that occurred repeatedly as women spoke about decision-making:

Because I had a very serious relationship with that child, and to be carrying it around, wondering whether I was gonna kill it or not was just very serious, I mean, it's feeling like you're going to murder something that you're very close to that's inside of you, when you have the choice not to, and you're choosing to, you know, you're choosing the most difficult thing. (Margaret Thompson, 34, white psychologist)

Many expressed gratitude about having had a choice, despite the deep pain that accompanied its exercise. Knowing about a profound problem in a fetus and being able to choose to avoid bringing it to term was, in their estimate, better than living with the consequences of its birth. "It's better to know than not to know, better to have the choice rather than not to have the choice at all," said Marilyn de Soto, 34, Puerto Rican social worker.

Yet contained within this discourse of choice are the seeds of at least two other themes which bear mention. One is the subtle, perhaps fetishizing aspects of individualism implied in the concept of choice. Because the fetuses who are diagnosed grow within individual women's bodies, the socio-demographic circumstances of their development—older mothers, accessi-

ble, new reproductive technologies, the "background rate" of "birth defects" in all populations—may be harder to spot. This theme was brought home to me in the words of an African-American nonprofit education administrator who was also a single mother. Much of our conversation concerned the benefits and burdens of being on one's own as a professional and a mother. Yet when I used the language of "choice" to her, Doris Paul immediately responded, "Choices, choices.' 'Decisions, decisions' would be more like it. Because we're always called to crossroads and tests, they aren't things we seek, they're situations that befall us. And we go on, just the same."

Her reminder of the matrix within which individuals find themselves confronting decisions is apt, for it turns down the volume on individual volition, beckoning us to also attend to the structured situations over which individuals have very little control, but within which they regularly operate and compose their lives. This message was likewise echoed by a medical professional who wrote about her experiences with abortion after early prenatal diagnosis. For Rose Green (a pseudonym), the "choice" masked the non-choice of having produced an unhealthy child (Green 1992).

It is this second theme of "having produced an unhealthy child" against all odds and desires that also bears discussion. When I spoke with her a few weeks after she had terminated a pregnancy upon learning that her fetus had Down syndrome, one white lawyer quoted a recent popular book on pregnancy loss which includes a chapter on abortions after prenatal diagnosis: "The father was speaking of a double whammy of grief [in Kohn and Moffit 1993]. That's right. First you've produced this defective child, then you've gone on to have a devastating abortion. Who could possibly understand?" And others went on to speculate about the meaning of making a fetus that couldn't live, or couldn't live normally, especially when the diagnosis included mental retardation, a profound dilemma for the many constituencies who value normal intelligence:

I feel pity for my husband. All he can think about, the thing that torments him is: He's smart. I'm smart. The other kids are smart. How could this have happened to one of our children? (Donna deAngelo, 38, white homemaker)

After this, I really understood adoption much better. Because it can't be predicted how your child will be from getting your genes. And you don't need your kids to be genetic copies, they might be unlike you anyway. After all, there we were, two perfectly accomplished, intelligent, competent adults. And we'd made a baby who could never grow

into those things we most valued. For some, I know it's guilt. For me, it was astonishment. And overwhelming grief. (Pat Gordon, 37, white college professor)

And there was anguish expressed at having produced the "wrong" child, a theme which reappears in chapter 10. For example, Fran Goodman, 34, white nonprofit community organizer, said, "I always wonder when people hear (that we aborted a fetus with Down syndrome), there's still this thing like, 'Can't you have a healthy baby?' There's just a little piece of me which thinks they're wondering."

Diana Morel, a young Puerto Rican secretary, suffered a doubly devastating loss: First, she experienced the stillbirth of her first child from spina bifida, closely followed by an abortion when her next pregnancy was revealed on sonogram to be carrying a fetus with Epstein syndrome, a rare and inevitably fatal heart insufficiency. Yet she spoke to almost no one about her disorientation, grief and depression: "I'm ashamed. I'm ashamed that they'll blame me for the damages I made."

Taking Responsibility

The grief accompanying an abortion following prenatal diagnosis is thus multilayered. It condenses the pain of all pregnancy loss; the frightening fantasies accompanying the knowledge (but not the mediating and potentially resolvable phenomenological experiences) that one has reproduced in an unhealthy or otherwise problematic way; and the sense of responsibility attendant upon choosing to end a pregnancy which had been deeply desired.

It is this last point—the desire for a pregnancy that one is also ending—which haunts many of the narratives I collected:

Oh, I was so all right with that child, it was just me and that baby, I didn't want anything else. I was so contented that fall. Then, in one minute, it all turned around. I heard the doctor's voice, and the baby disappeared. Even though it was still kicking. And I was numb, I was a zombie. And I haven't recovered yet. (Nancy Tucker, 36, white college professor)

I spent five months doing everything right, nurturing that baby, eating right, trying to slow down and take good care of myself. Not one drop of alcohol. And on the night we found out, I wanted nothing but sleeping pills. Me who had never once taken a sleeping pill in my life!

"I can't stand the kicking." I remember crying that to Shelley (the obstetrician) when I asked for a prescription. "Have a drink, it will put the fetus to sleep," she told me. "A drink!" I said in horror. "I can't drink, I'm pregnant!" (Pat Gordon, 37, white college professor)

It was hard, it was just too hard. Because I really, really wanted that baby. I try not to think about it now, to maintain a positive attitude about the next one. If I think about it, I'll just start crying all over again. Because I really, really wanted that baby. (Carolyn Williams, 36, African-American postal worker)

Few studies assess the impact of receiving a positive diagnosis. Those that exist describe great grief and personal and interpersonal stress accompanying the experience (e.g., Black 1984, 1994; Blumberg, Golbus et al. 1975; Furlong and Black 1984; Kenyon, Hackett et al. 1988; Kolker and Burke 1993, 1994). This disorienting pain and intimate upheaval are particularly pronounced in the case of women who have received ambiguous diagnoses.

In some sense, of course, all diagnoses are ambiguous: No matter how clear-cut or relatively common a diagnosis is, one always can fantasize that the test was wrong or mislabeled; one can believe that *this* potentially fatal heart defect or *this* case of mental retardation will be outgrown. A few of the women I interviewed took the potential variability of their fetus's condition very seriously, undertaking what I have come to think of as social research to better comprehend the range of difficulties associated with the diagnosis. Of the fifty women receiving positive diagnoses whom I interviewed, five reached beyond medical experts to learn about the family and community lives of children with the conditions they knew their fetuses to have. In these cases, the women found obstetricians and genetic counselors compassionate toward their dilemma, but fundamentally unprepared to assist in a social, rather than a medical, assessment of the situation. Several commented that they had volunteered or been recruited to act as "peer counselors" after the genetics team learned about the decision-making work they had undertaken. Like Pat Carlson (chapter 7), who visited a neighborhood home for retarded adults before deciding to keep her Down syndrome pregnancy, such women moved beyond the medical network, where a richer picture of life with a disabled child can be gleaned. Jane Butler, for example, asked the genetic counselors to find her a parents support group for parents of children with Down syndrome (her fetal diagnosis). She and her husband visited one classroom and spent an hour with a family:

I talked with this couple who had a kid with Down's, and I thought they were terrific. The kid was nice, and they seemed like a fine family. But they'd been married almost twenty years when it happened, had raised three other kids, and were confident of their commitments. Stu and I have only been together for two years, and it's our first baby, and what if the strain were too great? What if we never got the chance to have a normal kid? What if we broke up over it? (Jane Butler, 35, white secretary)

She thus contextualized the differences in marriage and family life which led to her abortion decision. And she and her husband felt satisfied that they had "done their best."

Margaret Thompson's fetus was diagnosed as having a neural tube defect biochemically, but the lesion could not be located on initial sonograms. She carried the fetus for a month, visiting schools and clinics where children with spina bifida received services. She found the nurses, teachers, and mothers "very upbeat," but she was also overwhelmed by the amount of work and the medical crises which punctuated the daily lives of the children and their families. "I really wanted her [the nurse] to tell me not to have the child, but she couldn't do that. She made it quite clear that it would be a full-time job, and not easy, but very rewarding, that this child would accomplish a lot." When the lesion became visible many weeks later, she and her husband chose to end the pregnancy:

The thing that stood out in my mind the most when I saw that second sonogram where it didn't look like there was anything wrong was, I remember seeing his little penis—it just tickled me, it was so tiny and so straight up. [Later, when the spina bifida was visible], [k]nowing that my child could never have sex, and he'd never be able to have an erection, which was pretty clear once we saw where the injury was to his spine, well . . . that did me in, more than anything else. (Margaret Thompson, 34, white psychologist)

Conscientious research and familiarity with services were not sufficient to balance the sense of grief and loss she and her husband assigned to the imagined future their fetus would have.

Some women must cope with not only the existential dilemmas entailed by any prenatal diagnosis, but the problems inherent to an ambiguous diagnosis. Some conditions are so rare as to be interpretable only through "guesstimate" from the viewpoint of biomedical experts; others have poten-

tially variable consequences—some acceptable, and some unacceptable—to the pregnant woman and her supporters. Under these circumstances, decision-making may be protracted, as pregnant women visit additional experts, undergo additional tests, and live with additional stress. Marie Mancini's fetus, for example, was diagnosed with satellites (additional, patterned genetic material on the ends of chromosomes) in a configuration so rare that the geneticist supervising her case at a major research center could locate only fifteen other clinical reports of the same condition. She tried to follow the outcomes of those fifteen, which were highly variable, and included both "normals" and infants who were profoundly neurologically impaired. Her abortion decision was made in part because there was so little medical information, and even the "normals" in the literature had been followed only through infancy. Jamie Steiner, a white health educator who chose to have amniocentesis at the age of 33, received a doubly ambiguous diagnosis: A sonogram revealed a large fetal oomphalocele, a midline closure defect, in which gut organs protrude and abdominal muscle is missing. The chromosome study also revealed satellites. The geneticists were hesitant to link the two problems, one of which might well be correctable by neonatal surgery, but with unknown success rates, the other of which might or might not have clinical consequences.

The whole time they were doing more sonograms, checking the chromosomes, confirming their diagnosis, that whole time I kept thinking, "I'll keep the baby, I'll go to the hospital, I'll nurse right there. Who knows, in a year, two years, this baby might get better." I just kept romancing that, wanting to believe that I could be that kind of mother.

Alternating between hope and despair, with no definitive biomedical pronouncement of the seriousness of either condition, Jamie and her husband took a month to make their decision to abort. Likewise, white artist Sybil Wootenberg took a month to undergo extensive sonogram studies and to visit the neonatal surgery unit at Elite Hospital in another state, after her fetus was diagnosed with an oomphalocele. She consulted everyone—including her family pastor, a couple whose child had had an experimental oomphalocele repair, and the local feminist medical anthropologist—before deciding to abort. "I want to be a mother, I really do. But I'm 41, on a second marriage, it isn't all that I want. My mother died in her forties. There's got to be more to life than this!" After she finally ended the pregnancy, I asked Sybil how she had tolerated a month's delay in reaching a decision while the fetus kept growing and kicking. She said: "Maybe it's sick, but hav-

ing all those sonograms, consulting with all those doctors, having this big problem on my hands—it made me into an interesting case. And it kind of replaced the baby. If I was losing the baby, at least I was becoming an interesting case.” Here, expert interpretation of the technological inscription and reinscription of a fetus provided some of the benefits of “specialness” which she had felt as a pregnant woman. A technological substitution thus masked some of the pain, inventing a new biomedical status for pregnancy loss.

The Burdens of Knowledge

Sometimes, diagnosed conditions are inherently slippery from a social or cultural perspective. This is surely the case with sex chromosome anomalies, a collection of atypical diagnoses involving too many or too few sex chromosomes. People born with such conditions may well never be diagnosed, as their appearance may fall within the range that they and their peers code as “normal”; their only presenting “problem” may be infertility due to un- or underdeveloped reproductive organs (either visible or invisible). Some sex chromosome anomalies may not even have been coded as “biomedical problems” until relatively recently. For example, one genetic counselor told me that the first time she encountered XYY chromosomes was in the karyotyping of a doctor at the hospital where she worked. After a prolonged period of infertility in his marriage, the doctor had sent both his own and his wife’s blood samples for chromosome analysis. The condition had obviously not affected anything else in his life sufficiently to require this clinician to seek biomedical help. Men with small penises or no sperm in their ejaculate also *may* have such chromosomal conditions and never know about them. But the range of syndromes accompanying sex chromosome anomalies is wide, and includes substantial risk of learning disabilities, mild mental retardation, growth and stature anomalies, and in the case of Turner’s syndrome (XO, a female with a missing X chromosome), atypical neck, fingers, and possible heart problems. Additionally, men with extra Y chromosomes (XYY) were thought in the 1970s to be at risk for antisocial, violent, or even homicidal behavior. While such an interpretation has long been ruled scientifically spurious (Duster 1990; Green 1985; Hook 1973), it has had a lurid half-life in popular media and fantasy. And when genetic counselors describe sex chromosome anomalies as part of the range of potential findings in amniocentesis, it is not uncommon for couples to ask if these conditions are related to homosexuality, as I indicated in chapter 4. Widespread phobias and fantasies thus intensify the meanings attached to the interpretation of sex chromosome problems.

Throughout previous chapters, I have narrated several stories of those receiving sex chromosome anomalous diagnoses; some women chose to end their pregnancies, while others continued them. About half of the women receiving this diagnosis continue their pregnancies, according to New York counselors (cf. Petrucelli, Walker et al. 1998; Robinson, Bender et al. 1989). In my interviews with women or couples who had received such diagnoses, I was struck by the burden of knowledge: All of them wondered whether they could bear to raise a child with a “hidden” problem that would unfold in adolescence, about which the child would initially know nothing but the parents would be informed.

Would he blame us for this, blame us for knowing? (Rosaria Lugones, 29, Colombian homemaker)

I thought to myself, if you didn’t know these things that would be one thing, but knowing this, how would this child feel, knowing that you knew? My husband was very clear; he’s a man, and he started explaining psychology to me. It’s rougher on boys. . . . The kid will be teased to death because boys are more . . . Ending up as a male with a small penis and sterile, it was hard to sort it out, about the kid feeling so bad. If he ended up mentally retarded, my husband would be furious, but *he* might not mind. But if he ended up normal, *he’d* be so furious, “How could you have let this happen to me?” There was no good answer. (Sylvia Lin, 43, Japanese-American special-education teacher)

The burden of knowledge forced potential parents to articulate their own submerged values as they debated their fetuses’ futures. One genetic counselor, for example, encountered two patients who chose to abort a fetus after learning that its status included XXY sex chromosomes (Klinefelter’s syndrome). One professional couple told her, “If he can’t grow up to have a shot at becoming the president, we don’t want him.” A low-income family said of the same condition, “A baby will have to face so many problems in this world, it isn’t fair to add this one to the burdens he’ll have.” And a young lawyer who very much supported his wife’s decision to end a pregnancy in which Klinefelter’s had been diagnosed mused about his own parenting skills:

So he would have had this sex chromosome thing, he might have been slow, and he was going to be aggressive. I didn’t know how to handle a kid like that. When he got rowdy and difficult, could I be a committed parent, or would I have thrown up my hands, thinking, “It’s in his

genes"? [Author: What if you hadn't known through prenatal diagnosis?] I'm sure if it had just happened we would have handled it. But once you know, you're forced to make a choice. (David Kass, 35, white lawyer)

Diagnoses may be socially as well as biomedically ambiguous. I was present at Genetics Rounds one Thursday at Middle Hospital when a case of fetal chromosome breakage was presented. In this instance, a high percentage of broken chromosomes (present in thirteen out of thirty-three cells examined) were found in one sample; such a finding might indicate a rare underlying genetic syndrome including, in the worst cases, fatal anemias. But it might also well indicate that a transient infection had broken the chromosomes; once the infection passed, the next sample should reveal a growing percentage of unbroken chromosomes. In that case, the fetus might well be normal. The staff discussed the case extensively, understanding that a pregnant woman might be panicked by such an anomalous situation, and abort because she could not know what the outcome was going to be. They therefore decided to recommend a second amnio, in the hopes that it would lend weight to the "transient infection" hypothesis. They also considered and set up a more experimental (and hence, riskier) procedure, PUBS (percutaneous umbilical blood sampling), which would draw fetal umbilical cord blood directly, in the hopes of securing a faster and more definitive diagnosis for the mother, who was already eighteen weeks pregnant. They set in motion the cumbersome bureaucracy, both at the pregnant women's HMO and at Middle, to get rapid approval for the procedure. They additionally recommended high-resolution sonography, and a karyotyping of a maternal blood sample, to rule out other less likely anomalies that might be responsible for the breakage.

With these multiple strategies in mind to preserve the pregnancy in the face of an ambiguous diagnosis, Rena Coron, a 43-year-old social worker from a Dominican background, was called in. She had already spoken once with a genetic counselor, and knew that there was something anomalous in her fetal results. I was present at the counseling session, and spoke with Rena many times over the course of the next several weeks. The initial counseling session was dramatic. After the head geneticist had gone over the findings and offered both a second amniocentesis and PUBS, Rena erupted in consternation and anger:

I cannot wait emotionally another ten days to see if I can look at kid things and maternity clothes, or see if I am considering abortion. I'm

a single mother, I've got a 14-year-old son, I'm a professional. I have to let my job know right away if I am taking maternity leave or not. I simply cannot wait.

Various members of the genetics team tried to bring the conversation back to the possibility of a normal, or near-normal outcome, encouraging Rena to have both an additional amniocentesis and high resolution sonogram that very day. But she interrupted their medical discussion once again, saying, "My fiancé had another woman who got pregnant for him, and the fetus died during labor. What is 'fetal distress'? Is this in any way related?" Trying to reassure her that "fetal distress" was a broad-spectrum label, and not a genetic diagnosis per se, the team explained PUBS, hoping that even a high-risk procedure would be more appealing than an automatic fetal death. But Rena went on:

I must be honest with you. If, after the sonogram, I choose to end this pregnancy, are you saying you will still want to study the fetus? I was very excited about this pregnancy, I really wanted this baby. But I'm 43, I'm reconsidering. I'm not sure that pregnancy is really the direction in which I want to go. I work with learning disabled; with emotionally disabled, this is taking its toll. . . . My fiancé and I are pulling apart; we may well not be together by the time this situation is resolved.

At this point, the chief geneticist interrupted the consultation, ostensibly to consult with the radiologist about the impending sonogram. But he asked the head genetic counselor and me to accompany him. In the hall, he organized an emergency meeting, saying, "I do not think this woman wants to continue this pregnancy at all. Things have changed in her life, the boyfriend is easing out of the picture. She has a right to end it if she wants to. Aren't we imposing our values on her, keeping her pregnant for longer and longer, to study a case?" Our "team" was thrown into consternation; counseling needs for the woman clearly superseded fetal diagnosis. After a few minutes, we reentered the room, repeating that the sonography team was ready to examine the fetus if she wanted. But we added that she might like a few minutes in a quieter location to consider the stressful "facts of the case." Alone with me and one counselor, Rena was quite explicit:

I've prayed over this case. I'm a strong person, I've gotten through other difficulties, I'll get through this one. My relationship with my

fiancé is going downhill. The more I tell him, the less he responds. This may lead to a parting of the ways. My son really wants this baby; he's going to be miserable. But I have decided to end it. Here and now.

The counselor took a deep breath, abandoning chromosomes in favor of abortions, and started to describe the possible procedures. For several weeks, I called Rena back, inquiring about her abortion experience, her recovery, her support system. I learned a great deal about her mother, son, and women friends, and a bit about her (by now ex-) boyfriend. What I never learned was the salience of broken chromosomes: The ambiguous diagnosis, so central to the work of a conscientious genetics team dedicated to setting up cutting-edge services to diagnose Rena's fetus, had receded into the mists. It had kicked off a decision-making process in which social ambiguity—of appearance, professional commitments, and, above all, the status of a love affair—far exceeded the weight of genetic material.

Late Abortions

However clear-cut or ambiguous a positive diagnosis may be, the circumstances of late abortion are always difficult. In the United States, 89 percent of abortions occur in the first trimester; only 6 percent occur between the thirteenth and fifteenth weeks of pregnancy, and only 5 percent after the sixteenth week, including virtually all amniocentesis-related abortions (Epner et al. 1998; Koonin, Smith et al. 1996). The larger share of second trimester abortions are performed on teenagers, young women without adequate social and financial support, or women with extremely irregular menstrual cycles who didn't gauge the onset of pregnancy correctly. For these women, the grueling process of ending an unwanted pregnancy between its fourteenth and twenty-fourth weeks (the legal limit for termination in the state of New York) brings unambivalent relief, even if the abortion procedure is difficult. But for the women receiving positive diagnoses through prenatal technology on wanted pregnancies, the situation is different. They describe their abortions with great ambivalence, often contrasting themselves with the teenagers and other "misfit mothers" they are likely to meet in the hospitals and abortion clinics where their terminations are performed.

This distinction between "good mothers in bad situations" and "girls unfit to be mothers," that is, between "good aborters" and "bad aborters," was one I initially resisted. As a longtime reproductive rights activist and someone who had done volunteer abortion counseling during the period directly before and during its legalization, I knew that an abortion decision is

always a complex matter. Yet I was forced to recognize the *cultural* judgment that many women with positive diagnoses make about their own circumstances: They considered themselves to be appropriate mothers, and therefore, tragically, appropriate aborters. While they often expressed compassion for teenage girls "in trouble," they did not want to be identified with them in any social sense:

These girls, they just don't want their babies. And it's a good thing; What kind of mothers would they make, anyway? They're here for a second, maybe a third, abortion. They can't be worried to do the right thing. Later, maybe later they'll understand. But it's just craziness for us, being put into a cattle car with them. It's a real mill, and what makes it worse is, the rest of them just don't want their babies. (Marilyn de Soto, 34, Puerto Rican social worker)

You know, I was the biggest one there. You could really see my stomach, and I kept saying to myself, I'm not just here having an abortion, I'm here taking out a child that needs to be taken out because of a reason. Some of the women, the girls, they're just there to take it out because they don't want it. It was hurting me more, and I was like, I was sure it was because that's something beautiful to me, having the baby, that's why I'm crying over it. (Iris Lauria, 29, Puerto Rican hospital housekeeper)

This was something I had to do. For these girls, it was just a lousy method of birth control. (Doris Paul, 43, African-American nonprofit education administrator)

And what stands out in my mind is that there was this very young, beautiful teenager, a young Asian girl, and while I was resting, you know, recuperating, waiting to go downstairs, she got up from the cot and stepped on the scale, you know, to see if she'd lost any weight. I just about died. I felt so bad for her, Oh, Jesus! I just felt bad like, she'd missed the whole point. Maybe she's lucky to have been, you know, so stupid. But it's a fucking tragedy to be so stupid about something so valuable. (Margaret Thompson, 34, white psychologist)

Satisfaction or dissatisfaction with delivery of abortion services—on maternity wards or in clinics (often referred to as "mills")—were tied closely to the care women received: Some found the nursing "fantastic," "compassionate,"

or even "very important—like, they made it clear this was a tragedy, I wasn't having a baby, even though I was on the maternity ward. I'll never forget them for that" (Nancy Tucker, 36, white college professor).

Others were appalled by the negative judgments of nurses who hadn't read their charts and therefore assumed they were being "irresponsible" to have waited so long to abort; or nurses who made their personal disapproval of abortion in general known. Some doctors were praised for their compassionate and professional manners: One obstetrician/gynecologist used by several of the women I interviewed reaped especially high praise because he called at home frequently after the disturbing results were forwarded to him, and after the abortion. He was explicit in his symbolic dissociation from the abortion procedure, sending his patients to a "real pro" who "only did abortions," so that he himself could continue to "only bring life into the world."

This physician's words alert us to the symbolic issues involved in late abortion after prenatal diagnosis: Many women wanted a clear-cut boundary established between pregnancy-leading-to-life and pregnancy-leading-to-death. While some decried "impersonal" or "anonymous" doctors, two women who had received private abortions at Elite and Middle Hospitals appreciated the good care but wished they had attended a "mill." There, they reasoned, the reality of making the pregnancy "really gone" or "a faceless mistake" would have been clearer, unlinked from "regular" pregnancy care. Moreover, laboring to give birth to death, when a woman wanted to be birthing a healthy baby, was a situation described again and again throughout these interviews. The symbolic dimension was also brought home to me in the complaint of Doris Paul, whose longtime HMO obstetrician/gynecologist personally performed her late abortion. Instead of feeling well-attended, Doris protested the confusion she felt about breached boundaries: "He delivered my daughter. I mean, how can he do both things, deliver Liza one year, and kill it [the fetus] the next? It was confusing. After that, I didn't want him to be my doctor anymore. I actually changed to the nurse practitioners at the HMO."

This conflation of labor with abortion is material as well as symbolic, as it reflects a common experience, depending in large measure on the method of termination used. There are three basic methods for terminating second-trimester pregnancies; two require the woman to go through active labor to deliver the fetus. Traditionally, an installation procedure requires the transabdominal injection of either saline or urea directly into the uterus. These substances cause the placenta to separate, killing the fetus, which (eventually) brings on labor. To hasten labor with installation procedures, or as a substitute for them, hormonal (prostaglandin) vaginal suppositories are used in the

majority of late abortions. The timing and intensity of labor are easier to control with prostaglandin, but it often produces side effects like fever, chills, nausea, and diarrhea. Prostaglandin-induced labor without transabdominal installation is safer for the laboring woman, as it removes the slight but potentially fatal risk associated with shooting lethal chemicals directly into her abdominal cavity, if the uterus is missed. But in addition to the potential side effects, prostaglandin-induced abortions include a 5 percent risk that the fetus will be born alive. In either case, and usually (but not always!) with pain medication, women labor on average ten hours to deliver a dead fetus. The third method of late abortion, less widely available in the United States (but quite available in New York City, depending on a woman's health care provider services) is the D&E (dilation and evacuation). It is safer for the pregnant woman, but requires much more active work on the part of the physician and her or his operating team of anesthesiologist and nurses. Prior to the procedure, the woman has laminaria—thin sticks of specially prepared seaweed—inserted into her cervix. As they absorb moisture, the cervix is dilated. This causes cramps which may range from mild to extremely severe. Twenty-four hours later, while the woman is under general anesthetic or heavy sedation, the fetus is removed surgically in an operation lasting from fifteen to forty-five minutes. Recovery is usually rapid, and there are few complications.

While I have described these procedures in medical and objectifying language, all carry a heavy load of physical and emotional suffering for the women involved; D&Es are also described as unsettling for some of the health care providers who perform them. As both a researcher who directly collected fifty late abortion stories, and heard countless more from counselors, and as a woman who has endured this experience, I have a strong bias in favor of D&Es. They are over more quickly, and do not involve the physical and emotional toll of labor. But the fetus is usually dismembered, a fact which was problematic for some women and their supporters. Several worried about the exact moment at which their fetus died, and whether it felt pain. And one Orthodox Jewish woman who aborted after a sonogram diagnosis of anencephaly told me she found the description of the D&E too stressful, choosing labor induction instead: "What decided my mind was no remains. I needed to take home the baby, even in a coffin, to bury it properly. I couldn't live with the idea of no remains, no one to visit in the cemetery" (Tamara Levkovitz, 34, white private school teacher).

But several women who were given no option to going through labor to deliver a dead fetus railed bitterly against their service providers for not giving them a "quicker way out." Despite their safety and "relative" ease, D&E

procedures are sometimes rejected by physicians, for they require additional training and active intervention from the medical staff, who may object to the grueling work, or suffer OR burnout.⁴² Moreover, labor-induction procedures require little work on the part of the physician, who need only be present to administer the initial drugs; after that, the doctor can depart, leaving the nurses completely in charge of highly variable labors. Differences of status and skill in the medical hierarchy may thus influence the available procedures. Moreover, a dismembered fetus is harder to study for pathology; some doctors thus suggest that their patients choose labor-induction abortions in order to better preserve fetal tissue as a "contribution to science." But many women resented the punitive nature of laboring to bring forth death when other alternatives were possible. Once again, the message is simple to interpret: There is no good way to exit the bad script of late abortion.

Fetal Remains

And for those who choose (or are given only the option of) labor-induction abortions, a relationship to the external fetus (as opposed to the internal fetus) must be worked through. After delivery, women and their partners may choose to see or not to see, to hold or not to hold. Some, like Tamara Levkovitz, may want to bury, but this raises a complex political issue which I will describe below. In my research, those who chose to hold or examine the fetus described many feelings: grief, pity, admiration for miniature but visibly normal features of babies whose abnormalities they may have feared and had certainly rejected.

I never decided, but when he took the baby out, I immediately said, "Can I see it?" And he was a little doll, seven, eight inches long, perfectly formed, a little tiny baby doll. He was beet red, and I couldn't see anything wrong but the nurse knew, she came forward, she showed me where the signs of Down syndrome were. And then the doctor stepped in and he showed me, too. And I think they did it well, so I could be at peace with the little doll of a baby, so I would never think that just because he looked so well-formed, I'd never think there had been a mistake. (Meeta Cabron, 39, Nicaraguan photographer)

They wrapped her up so I wouldn't have to see the head [where a portion of the skull and brain were missing], and she didn't look so deformed, she just looked beautiful. And peaceful. (Tamara Levkovitz, 34, white private school teacher)

They [the nurses] were great, only I didn't want that little baby whisked away so fast. God, it was so small, such a tiny baby, such a great loss. I started weeping immediately. (Johanna Gertz, 36, white community organizer)

A few women who chose not to hold their dead fetuses later expressed regrets.

The remains of fetuses are a highly political matter (cf. Casper 1994a, 1998). In New York State, aborted tissue must be checked by the hospital's pathology department. This regulation has medical utility, enabling diagnoses to be made or confirmed and monitoring abortion services. But it is also a symbolic statement claiming political turf in the abortion controversy at the state and city levels: Here, fetuses are not babies, they do not receive birth certificates or death certificates below twenty-four weeks, the legal limit to abortion and a few weeks short of what is now considered "viability."⁴³ While such regulations keep right-to-life movement activists at bay, they make retrieval of fetal remains for cremation or burial a daunting, usually impossible, task. Several women mentioned how distressed they were by sending the fetus to pathology:

When the doctor took a tissue sampling I asked him why, and he said, "To send to pathology to confirm the diagnosis." And I started howling, I was just screaming my head off: "If there's anything that even possibly needs confirming, what am I doing here?" (Michelle Kansky, 38, white public school teacher)

Several women, including Tamara Levkovitz, managed to circumvent those regulations, retrieving their dead fetuses for burial, usually with the help of sympathetic obstetricians. But others had to find symbolic alternatives. One described burying ultrasound images of the fetus, and another told this story in her letter to me:

We baptized our little son in the delivery room. We put the sonogram picture in the family Bible. No one can tell us we did the wrong thing, no matter how much they don't believe in abortion. He's gone now. But he *was* real. And abortion is real, and sometimes necessary. (Lena Jarowski, 36, white homemaker)

The reality of family mourning, the demands of ceremonial closure, the rituals of transition so salient to intergenerational connection, all require what

biomedicine cannot here provide: A material anchor with which to locate and condense the end of a desired pregnancy.

The Calendar of Grief

The grief and mourning which come with the territory of what is so antiseptically labeled "selective abortion" require more than ritual closure: They also require time. The particular work of mourning a desired pregnancy which one has chosen to end shares much with other forms of pregnancy loss, like miscarriage, stillbirth, and neonatal death. Its markers thus include the secret calendar of failed anniversaries: Due dates, the date on which a woman first learned she was pregnant, the celebrations that never got to happen are all present in the stories women told:

Rosh Hashonah was my due date, so I was wondering, "Will I be home for the holidays, will I go to Schul, or will I be in hospital?" And then, after this, I was totally disoriented when the holidays came around. I didn't understand where I was supposed to be. . . . Sometimes, when I go to the cemetery, I take Shera [her daughter] with me, as a comfort blanket. Now I'm waiting until I can put up a permanent stone [in the Jewish calendar, one year after a death]. Maybe then, I won't need her to come with me anymore. (Tamara Levkovitz, 34, white private school teacher)

One of my best friends was pregnant, due two days after me, and we had such great fantasies of pushing strollers together, raising them as friends from birth. When I ended my pregnancy, I spent a lot of time working it through, so I could welcome her baby, whose birthday would always, forever, not be my baby's birthday. (Pat Gordon, 37, white college professor)

The calendar of grief may extend across a whole social generation. Genetic counselors at Middle showed me an eloquent letter they received from a woman whose son was born with multiple congenital anomalies more than a decade earlier and died two hours after birth. At the time, the mother was so distraught that she could not bring herself to hold the baby, whose appearance she found frightening. Thirteen years later, she wrote to ask whether the genetics team still had the photographs that were taken as part of the pathology report. As a Jewish mother, she felt the need for closure at the season in

which her anomalous non-son would have made his bar mitzvah and been accepted into her religious community as a young adult.

And mourning is quite embodied: Many women recalled the discomfort—indeed, pain—when their milk came in, preparing them to nourish the baby they didn't have. "It was like such an insult, those rock-hard breasts, like pouring salt on the wound," said Megan Johnson, 41, white writer.

Others recalled how they obsessed about the return of their menstrual cycles, wanting to reclaim their nonpregnant bodies. Many needed cyclical markers to try to imagine or establish another pregnancy, a subject that became an obsession for some women:

Now I'm on hold; I'm just waiting for the next period, the next pregnancy. Only he [husband] wants me to get my tubes tied. I need to complete this, he needs to end it. So we fight a lot. (Marilyn de Soto, 34, Puerto Rican social worker)

I'm selfish: Having and raising babies is the center of my life. All the great moral and ethical moments come to you, they shoot right out at you, as you watch a child unfold. This one was unfinished ethical business. I needed to replace it, to finish the cycle. (Leah Rubinstein, 39, white homemaker)

Unfinished business, that's what it is. I try to maintain a positive attitude, but it's just unfinished business. Maybe I'll be better once I'm pregnant. Again. (Nancy Tucker, 36, white college professor)

Some women interviewed after a subsequent pregnancy recalled the fear attendant upon waiting for a "healthy" outcome:

I was just on automatic pilot. Like I knew too much to be happy no matter what the tests said. I knew that something could always go wrong. And at the birth, Shelley flipped the baby over the screen, she said, "Look, Pat, ten fingers, ten toes. Now you can relax. Go to sleep." And I did. (Pat Gordon, 37, white college professor)

We just ate up the telephone lines, me and Hannah [a woman who had experienced a stillbirth]. No use talking to Paul, he couldn't get it, how panicked I was. Once the amnio was clear, I guess I expected that second baby to die during labor. Like there was no end point to worry-