There is a certain kind of grim satisfaction in having one’s prophecies fulfilled, one’s concerns justified. I experienced that to a certain extent through the writing of *The Tentative Pregnancy* (1986) as hypotheses became theses, and I have felt it even more so as the years have gone by. To give a brief background of my project, the following questions and answers highlight the major issues discussed in the book:

What are the constraints on the choice to use or not to use prenatal diagnosis and selective abortion in a pregnancy medically defined as “at risk”? The constraints are probably just as one would expect: familial pressure, husband pressure, medical pressure, economic pressure. Some women experience the pressures all from one direction, while some women find themselves at the center of pressures working in powerful opposition to each other (husbands saying one thing, doctors another). Some women are better positioned to resist pressure, some less so.

What are the consequences of going through testing like amniocentesis—consequences for the woman, even when the results come back as desired? The pregnancy in its first half becomes overshadowed by the concern for what might happen during the second: If the possibility exists that her pregnancy may be leading not to a baby but to an abortion because of a “genetic defect,” the woman’s experience of the pregnancy, the
fetus, and of her own motherhood is profoundly affected. For many of the women I interviewed, a new state of pregnancy had been constructed: a pregnancy without a baby. The effects were an awesome silence from a belly growing larger—a belly to be hidden in big sweaters, not flaunted in maternity clothes. The fear of having to become the executioner of one’s hopes meant that any early movement of the fetus that was felt became denied, acknowledgment of the sensation of movement was delayed, the quickening slowed, awaiting a phone call.

What are the consequences of learning fetal sex, an often unasked question answered? Well, in many cases, perhaps not what one would expect. Certainly the sexual stereotyping that follows is of no surprise: boys kick, are strong and vigorous; girls squirm, are gentle, lively. But the effect on the mother is not what studies of son preference would lead one to expect: boys are conceptualized as other, different, separate—their mothers, to their own surprise, are disappointed. Girls, on the other hand, are considered part of a mother’s self, are welcome. Mona Lisa, it would seem, had just learned it was a girl.

What are the consequences of learning bad news? (Indeed, what is the definition of bad news?) The news is overwhelming. Too many dimensions need to be considered all at once: length of life, quality of life, physical abilities, mental abilities. Factors one person may find as decisive, another finds as ambiguous. To decide what kind of life is worth bringing into the world is to decide the meaning of life—and by tomorrow. A decision has to be made; in some cases a moving fetus has to be stilled, and quickly. When news is bad, it is very, very bad—much worse than I ever expected. Women use the language of murder, of infanticide. The responsibility is awesome: sparing your child from its life. Here is a grief that should move the world; but the grief gets silenced, trivialized. The keening of mothers has never made much difference in our world.

That, in 1986, is about where matters stood in my study of the tentative pregnancy. But the book had a subtitle and a subtext: Prenatal Diagnosis and the Future of Motherhood. This technology has consequences, I was convinced, not just for the relatively small number of women who were at that moment being defined as “at high risk,” nor even for the increasingly
high percentage of women who will in the future be defined as at risk as the technology becomes more widespread and ripples out, but for all pregnancies and for all who will mother. Genetic technology changes the very way in which we think about pregnancy. And here I find the satisfaction of the “I told you so” at its grimmest. There is no pleasure to be had in having seen where all of this was heading.

The conventional wisdom—the male-dominated, patriarchally focused wisdom—worried about prenatal diagnosis and selective abortion as either a type of, or a forerunner to, an acceptable form of euthanasia. If we don’t draw the line here at the fetus, people argued, where will we draw the line? Conversely, but from the same underlying perspective, some people argued that prenatal diagnosis was a valuable technology, sparing the fetus the anguish of potential existence under unbearable conditions. The argument then slowly shifted to a discussion of what conditions are unbearable, and just what makes them unbearable. To a large extent the discussion was, and is, a valuable and informative one. What makes that wisdom patriarchally focused, however (whether it comes out of the mouths and pens of men or women philosophers, activists, bioethicists, physicians, or genetic counselors), is that it puts the fetus at the center of all arguments. The only question addressed becomes: Are we behaving in the best interests of the fetus?

I spoke to women in my study. I looked at the costs to women. It has been very difficult for many people who have read my work to understand that focus. So what, they ask me, are the long-term consequences of the tentative pregnancy on “bonding” and infant development? The assumption, the bottom line of their argument, is that if something has no consequences for the child, no consequences exist. Genetic technology has consequences. It changes women’s experience of pregnancy. The use of this technology—of all the varied technologies of prenatal diagnosis and selective abortion and now of selective implantation—reconstructs pregnancy in men’s image.

What is pregnancy? This question lies at the heart of understanding the consequences of both prenatal diagnosis and the rapidly developing technologies of procreation. For women,
pregnancy is a slow process of separation; part of us goes on to become someone else. The whole, the totality that is self—at first slowly, with a flutter, a rumble, a movement from within, and then suddenly and dramatically at the moment of birth as part of ourselves comes out through ourselves, as something held inside becomes someone held outside—that totality shatters into two parts.

What happens when we use the vantage point of men to describe this experience of women? Reality is turned on its head. Babies are “expected” and then “delivered,” packages from outside. Babies “arrive,” they “enter the world.” And most insidiously of all, we “bond” with them—as if when the cord was cut, two became one, not one became two. Women do not feel babies arrive; we feel them leave. For us, birth is not a moment of attachment; it is a moment of separation.

Compounding the conflicting definitions of pregnancy and childbirth is a technology that further separates the baby from its mother—it separates the baby from the pregnancy. Conceptually, the fetus becomes a potential patient to be tested; visually, the free-floating fetus, made visible by its mother being rendered invisible, enters public awareness; and physically, a preimplantation diagnosis manipulates the material that will become the baby in a procedure conducted outside of the woman’s body. The technology we have developed and continue to develop reifies a male notion of pregnancy, of the making of babies. It assumes, and thus demands of women, that our experience parallel men’s, that we (like men) start from separation and come (and only with caution) to intimacy.

So what is pregnancy? For men, the focus is on the seed, the material that will become the baby. Even if we are belatedly recognized also as producers of seed, women still remain the place where men’s seed grows. The seed is essential, considered determinative; the place it grows is considered a variable. Seeds are culled, sorted, graded, evaluated. The good ones are to be planted, to be given space to grow. Women are merely the space.

Pregnancy thus becomes, when constructed from a patriarchal focus, a production process, the transformation of seed to baby. The effects of that way of thinking are now coming to
haunt us: as pregnant women are increasingly subjected to social control, we are seeing what looks very much like the regulation of untrusted, unskilled workers. And as a process of production, pregnancy becomes a service, the service ultimately becoming available for purchase. Surrogacy has become a thinkable thought; pregnant women are no longer necessarily the mothers of the children they carry within. Less a transformation of self, pregnancy has become a contractual agreement. It is to some extent, perhaps, an agreement between a woman and a man, but more fundamentally, it is an agreement between a woman and some genetic material. Thus, in effect it is an agreement between a woman and the controllers of that material—the father, the state, or the (purchasing) potential adopters.

The technology we develop grows out of this constructed contractual way of thinking, this perception of babies not as growing out of their mothers, flesh of their flesh, part of their lives, bodies, and communities, but as separate beings implanted within. The technology then reifies the ideology as we develop methods that allow us to create separate beings in test tubes, choosing which to implant. Preimplantation diagnosis is being offered as the coming alternative to prenatal diagnosis, and women may eventually come to be seen as just one possible site for implantation.

It is thus important to understand that this technology of prenatal diagnosis, and the specific technology of amniocentesis, does not come about in a vacuum. It develops in the context of all of the new reproductive technologies, including those that arrived with much fanfare such as in vitro fertilization and embryo transfer treatments for infertility. Amniocentesis has crept in more quietly, but it is part of the whole, occurring in a context in which women are more and more being seen as sites for fetal growth or, worse yet, barriers to fetal care.

An additional point of context is the fact that the technology is also developing in the midst of a major turn toward nature in the never-ending nature versus nurture debate. Articles about the genetic bases for the human condition appear weekly now. The search for "the gene for" anything and everything is on. In the past year there have been articles about the genetic bases for cancer, homosexuality, low birth weight, criminal behavior, altruism, and math scores. Recently a student of mine brought in
The Tentative Pregnancy

265

a clipping: "Study suggests a genetic predisposition to divorce" read the headline, but the reassuring subhead countered: "The genetic effect would not doom people to divorce, researchers said." Here was the New York Post's report of yet another twin study.

As any geneticist could explain, it is, of course, a far too simplistic vision of the way genes work. Genes don't "cause" divorce or cancer; genes interact with environments—the internal environment of the body, and the external social and political environments in which that body moves. But the image of a gene for particular characteristics, from alcoholism to sainthood, seems to persist. Some argue that it persists because it is actively constructed. Hubbard and Wald in Exploding the Gene Myth (1993) give an example of four newspaper articles in the Boston Globe on a single day: "Genetic link hinted in smoking cancers"; "Schizophrenia gene remains elusive"; "A gene that causes pure deafness"; and "Do the depressed bring on problems?" The article on "the depressed" relies on studies of twins the researchers believed to be "prone" to depression, finding that the more depressed twins had had more traumatic events, such as rape, assault, being fired from a job, and so forth. Because the depression was assumed to be genetic, the traumatic events were assumed to have been "brought on" by the depressed women themselves. Those of you who think that being raped or assaulted might cause the depression clearly are not thinking in genetically sophisticated terms.

The schizophrenia article isn't much better. Yet again, a gene for schizophrenia cannot be found, and yet again the article quotes a psychologist reassuring the public that the gene is there somewhere, just not yet found. The smoking article is perhaps the most interesting: it seems (it's hinted) that some people might carry a gene that makes them especially vulnerable to smoking-related cancers. If the gene exists, and the article says that there is only a "hint" of a "link" to such a gene, the researcher estimates that 52% of the population may have it: more than half of us are particularly vulnerable to cancer from smoking; the rest are just ordinarily vulnerable. Thus 48% of the population should not smoke and 52% of the population really shouldn't smoke.

The study cited about deafness is the only solid study of the
four. A gene relating their deafness was indeed found among the members of one extended family in Costa Rica. Typically, this would not be a newsworthy story in Boston; but, as Hubbard and Wald point out, it gives substance to the other stories: See, there is a "gene for" things. We just have to keep looking for that gene for getting raped, or becoming schizophrenic, or getting cancer from smoking.

What has this to do with amniocentesis and prenatal diagnosis? As the hunt for the "gene for" goes on, the primary population having their genes tested often appears to be fetuses. Genetic testing in amniocentesis, and in the related test of chorionic villi sampling, is supposed to tell us if the fetus has the gene for various conditions. As the realm of problems that are believed to be genetically grounded expands, the problems for which fetuses can be tested also expands.

All of this speculation is gaining ground as the environmental causes of illness, disability, and death grow both larger and more clear. Our scientists and our newspapers focus not outside but inside, looking not at class, but at chromosomes; they look not at pollution indicators, but at genetic markers. New York City declares it has no money to provide antibiotics for homeless children with earaches, while in the same week the *New York Times* carries an article telling of the wonderful breakthroughs being made in diagnosing the genetic markers for deafness. The deaf community signs its anguish and goes unheard.

It is in the midst of all this that trumpets sound the great fanfare to welcome the newest and biggest and best scientific project yet: mapping the human genome. The earth mapped and conquered, space well charted, the scientists turn to internal frontiers. It is not just the major chromosomal disorders, not just a few dreadful diseases they seek to pinpoint; they want the whole story.

The little bits of information will be offered by clinicians, by genetic counselors, by geneticists, and physicians to pregnant women. Genetic information, like all fortune-telling, works in probabilities, possibilities, and potentials. I see a tall dark stranger in your future: make of it what you will. I see an increased probability, on the order of 12%, of cardiovascular dis-
ease in your child when he reaches middle age: make of it what you will. Women anguish over the decision to terminate a pregnancy after a diagnosis of Down syndrome; after all, who can tell what degree of retardation the baby might have? Who can tell what physical problems it might have? Women anguish over these questions and then virtually all decide they cannot knowingly go through with it—they cannot deliberately bring a child into the world knowing what they know, however limited, about what the child would face. Women now will be given the bits, dribs and drabs, of partial information genetic decoding will offer—an increased chance of this, risk of that, probability of the other. Based on this information they will be asked to decide whether to terminate a pregnancy.

Genetic and medical information is never enough. Just as women have had to look not only at Down syndrome itself, but at what our society offers in its institutions, services, and support for people with Down syndrome in order to make their decisions, so too will women now have to look not just at increased risks of, say, cancer, but at increased use of cancer-causing materials. These decisions of whether to continue or to terminate a pregnancy are never “medical” decisions. They are social decisions.

Increased knowledge, without increased responsibility on the part of the society, translates to increased knowledge with the inevitable burden of responsibility on mothers. We are asking mothers to become the gatekeepers of life. We are individualizing social problems of disease and disability, medicalizing life itself, and doing it through the bellies of pregnant women.

I find the language of individual choice untenable in this situation. Women are asked to “choose” whether to bring a child with certain genetic predispositions into the world, but they are not given choices about the environment in which that child would live. When a women “chooses” aborting rather than bringing to birth a child with a particular condition or predisposition, she is doing so in a world that sets the parameters of that child’s life just as surely as genes do. Abortion can be the right choice, the moral choice, the only choice, but it, like birthing the child, is always a choice in a context.

When bioethicists debate reproductive choices and issues,
when Supreme Court justices think about them, they are understood to be the great moral issues of our time. When pregnant women face these choices they are defined in terms of "anxiety." Virtually all of the medical research on the social and psychological consequences of prenatal diagnosis continues to be couched in the language of anxiety. It is as if what the woman experiences awaiting the results of her amniocentesis is essentially the same emotion she experienced in seventh grade before a math test. And when she chooses an abortion, her reaction is most usually measured in terms of "depression."

I remember the first time I presented this research to a group of physicians. It was at a continuing medical education seminar held in Aspen. (They fit in some lectures early in the morning and then late in the evening, après-ski.) At 10 PM I was telling a group of doctors, legs stretched out, tanned faces gleaming with the day's sun, about how the women suffered when they aborted, following prenatal diagnosis. As I spoke, the legs pulled in; the men sat up. They got angry and began to argue. "My women," one said, "my women never felt anything like that. They are grateful. They have their abortions and then they have another baby." I thought of the women I had interviewed, of some of the cruel things they told me doctors had thoughtlessly said or done, and of their silence with their doctors. I thought, who would have the nerve to cry in front of this man, open grief up to him? Later, one of the wives came up to me. She had had a miscarriage a few years ago—just an ordinary miscarriage—but it had all come back to her as I spoke. Of course these poor women grieved and suffered, and, she continued, if her husband hadn't understood her grief, how could he have understood that of his patients?

Later, as technology for earlier diagnosis became more widely available, the climate began to shift. Now there was some openness to hearing about how hard later diagnosis was. Once chorionic villi sampling had become more widely available, once early amniocentesis had made results possible before the fourteenth week of pregnancy, the doctors suddenly changed their tune: late abortions are indeed traumatic; the old amniocentesis was indeed a problem. As is so often the case, having a solution enables people to recognize, or at
least to acknowledge, a problem. And early prenatal diagnosis does indeed help solve some of the problems of later prenatal diagnosis.

But I have to remember, too, a phone call I got one evening. A woman had tracked me down at home after having read my book. I got a fair number of such calls just after *The Tentative Pregnancy* was published. This woman told her tale—a tale I had grown to know quite well. She had had her abortion and gone right back to work. She was a physician, as a matter of fact. And then one afternoon a couple of weeks later, she couldn't take it anymore. She just started crying out of nowhere. Leaving the office and walking for hours, she found herself wandering in a bookstore at one point and, oddly enough, found my book. Standing in the store, she cried, recognizing herself and her grief in these women. She took a couple of months off, allowed herself time to recover from her loss, allowed herself to understand her loss as real, genuine, and worthy of grief rather than purely of gratitude. She thanked me, I thanked her, and just before she hung up, she said, "And think how much worse it would have been with an amniocentesis." "What?" "Oh," she said, "hadn't I mentioned? I had a chorionic villi sampling, and my abortion was at ten weeks."

Some say that doing testing earlier on will make the experience easier. It simply has to, doesn't it? And studies of women who have chosen earlier diagnostic techniques do indicate that the earlier techniques, even with higher risks of causing miscarriage, are chosen precisely because earlier abortions are supposed to be—are expected to be—less difficult (Kolker, 1990; Wertz, 1990; Zimmerman, 1989; Kolker, 1993). But just as a late abortion following amniocentesis might be easier and preferable to, say, euthanasia on an infant, and still be a tragedy in its own right, so too might an earlier abortion be easier than a later one, but still be experienced as tragic. We don't have to do a calculus of pain. This is, however, a technology founded on a calculus of pain, grief, and tragedy. It introduces that calculus into each woman's pregnancy. However one feels about abortion, whatever one sees as the consequence of all this testing for fetuses, the technology of prenatal diagnosis has changed and continues to change women's experience of pregnancy.
People will continue to be born with and to develop abilities and disabilities, strengths and weaknesses, resources and vulnerabilities. I do not really believe that those aspects of life will change, no matter how much mapping one does of chromosomal territory. But mothers will suffer and motherhood will have changed. That has consequences. That is of consequence.

ACKNOWLEDGMENTS

A version of this chapter appears as the introduction to the 1993 edition of *The Tentative Pregnancy* (W. W. Norton).

BIBLIOGRAPHY


