Introduction

The technology of amniocentesis was first developed experimentally from the late 1960s forward with and for women who were at high risk of transmitting chromosomal and genetic disorders. It quickly spread during the 1970s and 1980s to those sectors of the American population who had access to both the knowledge and payment plans that sanctioned its use, that is, overwhelmingly, the middle classes (Cowan, 1992, 1993; McDonough, 1990). Now another kind of experimentation and routinization of prenatal diagnostic technology is under way as women from much less privileged backgrounds gain access to the test and, increasingly, opt to use it (Hsu, 1989; MHRA, 1990).

For the past nine years I have been studying the social impact and cultural meaning of this “second wave” of amniocentesis in New York City, where the test is widely available to, and widely used by, women from diverse racial, ethnic, religious, and socioeconomic backgrounds. As a medical anthropologist, I am particularly interested in how this piece of reproductive technology intersects American cultural values in all their diverse complexity. Now New York City is not New Guinea, and prenatal diagnosis is not a secret initiation ritual. Nonetheless, standard anthropological methods of participant-observation
have enabled me to build a multilayered understanding of amnioncentesis.

Working in a range of New York City hospitals, I have watched more than 300 intake interviews with pregnant women from culturally diverse backgrounds who are potential candidates for the test, trying to understand their questions, silences, and responses to the information genetic counselors give them. I have also interviewed more than 60 women (and 15 men) at home after they have had the test to see what they thought about it, and scores who refused to have the test, to find out why a "routinizing technology" doesn't always stay on route. Thirty-five genetic counselors and ten geneticists spoke with me about the cultural diversity of their patients' backgrounds and about their own attitudes on prenatal testing, disabilities, and their variance in responses to the testing. An internship at the city lab revealed something of how technicians think about their work, while families in a support group for parents whose children have Down syndrome helped me to understand the difference between a medical and a social definition of a chromosomal disability. In studying so many overlapping layers, I hope to understand how women from diverse backgrounds experience the benefits and burdens of prenatal diagnosis, and to examine the problem of scientific literacy in general, and what genetic testing means in specific, in a multicultural society.

The Research

I began my research by working out of the Prenatal Diagnosis Laboratory (the PDL), set up by the Health Department of New York City in 1978 explicitly to provide outreach to the urban poor. The PDL is the largest cytogenetics lab attached to a public health facility in the United States. Its three to five genetic counselors are circuit riders, servicing both private (that is, middle-class) and clinic (that is, working-poor) patients in five to seven hospitals, and its laboratory analyzes amniotic fluids for 24 municipal hospitals. The population served by the lab is about one-third African-American, one-third Hispanic, and one-third white. But we should be cautious about such census categories. Recent Haitian immigrants coming from the society
with the poorest medical services in the Western hemisphere are lumped together with native New Yorkers whose families have been in this country many generations longer than my own under the category “African-American”; the “old migrants” from Puerto Rico and the Dominican Republic end up in the same census box as recently arrived, war-torn Salvadorans and Nicaraguans, and middle-class Argentineans and Colombians. And the exotic “white” race includes Polish, Italian, and Irish Catholics; Ashkenazic and Sephardic Jews; Greek and Russian Orthodox; Pentecostalists; and Anglican Protestants as if they were a unified racial group by dint of not belonging to the minorities under surveillance.

In other words, “race” glosses a constantly expanding inventory of differences, and the salience of those differences change as the populations who come to the city and raise their families there evolve. But the historical and contemporary complexity of New York’s fluid racial-ethnic map is often erased by the very categories of “difference” we are given. It is too easy to flatten this diversity into census boxes, each overgeneralized ethnic or racial group corresponding to a new stereotype. The same caveats apply to my more recent observations at Beth Israel Medical Center, where I am particularly interested in filling out my sample by observing working-class and lower middle-class patients sent for genetic services by the Hospital Insurance Plan (HIP), New York’s oldest HMO. Beth Israel, too, serves a richly multilingual, multicultural patient population, approximately seven percent of whom are drawn from New York’s Chinatown.

Findings

As an anthropologist, I am particularly interested in how issues of cultural diversity affect the range of responses to being offered an amniocentesis. But what I have found is that among New York’s richly multicultural patient population sent for genetic counseling, women’s access (or lack of access) to prenatal services where they are treated with respect and care influences their responses to prenatal testing far more than any specific cultural factor. That is, a woman’s socioeconomic class stand-
ing, especially as it determines the neighborhoods in which she and her family live, and the areas surrounding the hospitals that will serve them, has already shaped prior health care experiences and the feelings of trust or mistrust with which a pregnant woman undertakes a counseling appointment. A woman's comfort or discomfort with the scientific worldview and scientific language is also deeply affected by her class-based experiences, especially, but not exclusively, through education. While the stories people told me about their aspirations, beliefs, and practices during pregnancy are clearly marked by concrete cultural legacies, these legacies are deeply intertwined with experiences more broadly shaped by class differences. This interplay of ethnocultural and class resources is easily illustrated in the reasons women give for accepting or rejecting an amniocentesis.

It is an axiom of genetic counseling that middle-class patients (disproportionately white) usually accept the test while poorer women (disproportionately from ethnic-racial minorities) are more likely to refuse it. But that generalization needs to be analyzed. Private patients are likely to have prior knowledge about the test and to have already made up their minds to use it by the time they come for genetic counseling. They will not make a counseling appointment unless they are already determined to have the test. Refusers in this class thus rarely get counted. But among clinic patients, an appointment with the genetic counselor may be the first opportunity they have to ponder the significance, risks, and benefits of prenatal testing. They then make up their minds in a context in which their decisions become part of hospital statistics.

Moreover, many African-American and Hispanic women do accept the test. Refusal rates vary dramatically from hospital to hospital. At one city hospital where the clinic serves in majority a Spanish-speaking low-income population, acceptance rates are high: 70–80%. At another, with an Afro-Caribbean and Spanish-speaking population, acceptance rates are low: 30–40% (Hsu, 1989). We could go fishing for a cultural explanation about pregnancy beliefs, medical attitudes, and so on. But a more simple observation is this: The first prenatal clinic is a stable and welcoming environment; women tend to be very comfortable there and tend to trust the nurses. By the time they
arrive for an appointment with a genetic counselor, they have usually talked with a favorite nurse, often in Spanish, and feel competent to accept or reject the test.

In contrast, the second hospital has been a site of struggle over services for many years, and the prenatal clinic is a difficult environment in which to receive health care. Women (and often their young children) feel imprisoned in uncomfortable waiting rooms where they routinely spend two to three hours before being seen. By then the level of anger and frustration, exacerbated by the lack of communication, makes it much more likely that a woman will break a counseling appointment or sit through it in a state of distrust. Far more than simply "ethnic differences" are at stake in the microsociology of access to adequate and helpful medical services, and those various influences then condition acceptance rates.

The culturally specific, historical legacies of different communities also influence acceptance or rejection of the test. Such influences are neither simple nor straightforward, for they are deeply embedded in many collective histories of social, not just individual medical, risk. When I interviewed a 36-year-old Honduran UPS package inspector in a run-down neighborhood of Queens, for example, she seemed to have accepted an amniocentesis without great introspection. As the mother of two teenaged boys from a former marriage, she "just wanted everything to be all right." During the course of an hour's home interview, my tape was filled with her disinterested answers, interrupted by the flamboyant and sonorous testimony of her fervently Pentecostalist husband. He described his vivid visions of the infant Jesus protecting his own infant-to-be, swore that the prayers of his co-congregants had already healed all manner of potential problems the child might have faced, and used the occasion of my visit to witness the benefits of faith. He testified that Jesus had already cured fetal dim vision and a hole in the heart, two problems whose eschatology is central to both the Bible and discussions of birth defects. It was a stunning performance.

Later, Mari-Carmen walked me back to the subway, and without the pressures of husband or tape recorder told me that Pentecostalism was saving her husband, who had twice been
jailed on drug charges, and from whom she had separated because of his infidelities. Her chief worries centered on her older sons, both having problems in school, one involved with a neighborhood gang. If “having a baby for him” would stabilize the family, she would accept the pregnancy, and the amniocentesis, and any other advice the doctor gave her, just as she had accepted the Pentecostalist congregation. Without the benefit of this shadow interview, I might well have coded Mari-Carmen’s answers as “medically compliant,” an instance of a working-class Spanish-speaker accepting the authority of medicine rather passively. I might also have coded her husband’s intense Pentecostalist presentation as “Hispanic.” But once she described the real risks in her life—a dangerous neighborhood and substandard schools for her children; a husband involved in drugs and other threats to family stability—I came to believe that Mari-Carmen had accepted the amniocentesis as a very small part of a larger design for family stabilization she was actively developing. “Hispanic” values of family and community clearly influenced her ability to welcome both Jesus and genetics into that strategy. These cultural values, though, are mobilized in the specific socioeconomic context in which she now lives. There is no way to disaggregate the class-inflected risks of neighborhood and the illicit networks threatening her family from the cultural resources and values she used to protect it.

When I interviewed an African-American Wall Street secretary about her decision not to have an amniocentesis at age 37, she spoke about her husband’s reaction to the consent form they were asked to sign. The form only covered lab procedures for analyzing the chromosomes extracted through the test; it was not a permission to perform the test, which is inscribed in different documents. But the lab form, which is written in quite technical language (and often skimmed or skipped by those committed to undergoing testing) included a proviso to use discarded amniotic fluid anonymously for experimentation. Reading intensively, the husband was disturbed by this clause, citing the Tuskegee syphilis experiments and other examples of abusive research conducted on black people as his reason for rejecting the test. Scientific bureaucratese here touched a culturally and historically sensitive memory of racially abusive medical domination.
When a well-known, upper middle-class WASP economist heard about this research, she told me her own amniocentesis story: pregnant with a third child at 38, she read extensively in the medical literature, and discovered that the birthrate of live-born children with Down syndrome was 25% lower than the figures quoted for the prenatal detection of this condition. She reasoned that the test was less accurate (that is, that it produced 25% false positives) than the geneticists were claiming, and rejected it on that basis. The difference between the two rates (at midtrimester, via amniocentesis; at birth, among liveborns) is, of course, based on another "fact" which she failed to turn up in her reading: chromosomally atypical fetuses remain vulnerable to miscarriage and stillbirth throughout the pregnancy; late spontaneous abortions of Down fetuses account for the difference in rates. Her "informed consent" to reject the test was based on a strategy I have often observed among white, upper middle-class professionals: they "fight with numbers," testing whether the discourse of genetics actually includes their own particular case and can respond to their sophisticated but idiosyncratic statistical interpretations. They feel comfortable deploying the language of statistics, using this strategy to accept or reject the counselor's expertise. The white economist's rejection was thus based on her cultural values and background no less than that of the African-American secretary.

Attitudes, knowledge, and beliefs about disabling conditions are also highly variable, and they enter into the decisions regarding acceptance and refusal of the test. For example, in two cases of the same diagnosis (the sex chromosome anomaly, Klinefelter syndrome), the same decision to end the pregnancy was made. But in one case, a middle-class professional couple said they "didn't want the pregnancy if he can't have a shot at growing up to be president," while a recently immigrated working-class couple said, "it isn't fair to impose this burden, too, on a child." A young Puerto Rican welfare mother continued her pregnancy after a prenatal diagnosis of Klinefelter. When I interviewed her four years later, during a second amniocentesis for a subsequent pregnancy, she was confident about her growing son's abilities, stressing that Klinefelter syndrome was not a physical disability. "As long as he looks normal, I'll be there for him," she told me. It is important not to romanti-
cize her reactions; initially sent for amniocentesis because she had a sister disabled by spina bifida, she would have aborted for that diagnosis. And a few months ago I learned of a Puerto Rican family dilemma being played out over another diagnosis of a sex chromosome problem, which the father interpreted as a code for homosexuality, despite the genetic counselors' best efforts. When diagnoses involve sex chromosomes, they often index anxieties about the limits of the natural bases of sexuality. A Colombian manicurist, for example, married to a Dominican factory worker, received a fetal diagnosis of Klinefelter. At their counseling session, they did not express much concern about the 10–20% risk of learning disabilities or mental retardation that accompanies this syndrome, and they listened to discussions of gynecomastia (male breast enlargement) and micropenises without intense distress. But the husband asked, "Is this going to make him homosexual? I don't want that." And the wife said, "He won't be able to have children—I wonder if he'll blame us." Both expressed concern about knowing something hidden that the son wouldn't know about himself, at least until he was older.

Culturally specific heritages also enter into how children born with disabilities are assimilated into family life. An African-American welfare-dependent mother of three told me this story about the birth of her son with Down syndrome: She had been planning to put the newborn up for adoption, a decision she had reached shortly before his birth, due to the domestic stress and violence with which she was living. When the baby was born and diagnosed, a white social worker came to see her about placing the child. The mother asked what would become of her baby and was told, "We'll probably find a rural farm family to take him." "Then what?" she queried. "He'll grow up outside, knowing about crops and animals," was the reply. "Then what?" the mother repeated. "Maybe he'll even grow up to work on that farm," the social worker replied. "Sounds like slavery to me," answered the mother, who decided to take her baby home. This imagery and its legacy contrasts strongly the stories of many white mothers who often fantasize peaceful, outdoor, small-scale life as the perfect placement for their children with Down syndrome. The following
story was told by a white, Jewish nurse who had a seven-year-old with Down: "I read somewhere that there's a community for retarded people in the mountains, somewhere in Europe. They play music and they run a farm. Kids like this are very loving, they're good with animals, it's like the music of the universe is inside of them. If only the rest of us could listen, maybe they could teach us to hear it better."

The point of all these stories is quite simple: Those culturally specific, historical legacies deeply influence how the offer of an amniocentesis or an abortion for a fetus affected by a genetic disorder is placed in the foreground or background of consciousness. Some risks are more experience-near or experience-far, as anthropologists would describe them (Geertz, 1968), based on the ways in which class and culture shape any particular woman's aspirations for herself and her family, and the resources she has at her disposal when making a medical decision. The resources of class and culture are deeply embedded in any individual woman's particular life history, where they intersect the myriad personal experiences on which her understandings of medicine, maternity, abortion, and disabled children (among many other factors) are shaped. This complex intersection of what is socially structured and what is more individually acquired in any personal biography should alert us against accepting easy stereotypes to explain any particular woman's reproductive decision-making. Yet such stereotypes too frequently emerge when we attempt to generalize about cultural backgrounds. For example, Puerto Ricans, Dominicans, and some other Spanish-speaking groups appear far more concerned about visibly stigmatizing conditions (and more accepting of mental retardation), while white, upper middle-class women and their supporters are more likely to use a medical vocabulary and assume that mental retardation diagnosed in their fetus is cause for abortion.

It would be a mistake, however, to jump too quickly to ethnic-racial explanations of such differences in attitude for several reasons: First, the factors noted above—differential access, the problem of prior knowledge and familiarity with scientific vocabulary and world-view, and the issue of relative trust versus suspicion of their local health care institutions—all affect
what women will do. Second, as every counselor knows, indi-
vidual reproductive and life history are also powerful factors.
I spoke recently with a 42-year-old white middle-class woman
who was in the throes of making a decision to continue or
end a pregnancy after a diagnosis of trisomy 18, a profoundly
disabling and usually fatal condition. Her anguish about the
possibility of never being able to become pregnant again was
clearly central to the decision she was making. And several years
ago I interviewed an Italian-American Catholic homemaker,
mother of three, who identified with the right-to-life move-
ment, but who had aborted after a prenatal diagnosis of Down.
Among the reasons she gave was her strong love for her daugh-
ter, whose life she imagined would be taken over by caring for
the disabled sibling after her own death. She thus described her
abortion as “an act of love.”

The Impact of Prenatal Genetic Testing on Women

The impact of prenatal genetic testing should be assessed with
women's diversity of perspectives squarely in mind. Otherwise,
the design of future research and services will reproduce the
inequalities of access, relevance, and power women currently
already experience. We need to consider the implications of am-
niocentesis for the many women and their supporters whose
lives it affects: health care providers and pregnant patients;
parents of children with disabilities and the larger population
whose attitudes, knowledge, and beliefs about disabilities both
shape and are shaped by mass media, education, health care, and
other social services. Amniocentesis (or any other piece of re-
productive technology) intersects a woman's life in relation to
all its other problems and possibilities: class, racial, and ethnic
markers. Experiences with, and attitudes toward, a range of
disabilities all strongly influence a woman's response to the test.
We need to insist simultaneously on the collective and indi-
vidual nature of those orienting features each woman brings
to her encounter with prenatal testing. It matters whether one
is African-American, Polish- or Irish-Catholic, middle-class or
working-class or working-poor. But it also matters whether
this is a first or a fourth pregnancy, whether you have experi-
enced difficulties in becoming and staying pregnant, whether you had a cousin with Down or a neighbor who had hemophilia.

There is no simple "feminist" response to the question of whether amniocentesis (or any other piece of reproductive technology) is liberatory or socially controlling because it is always potentially both, depending on the weight various social and individual experiences hold in a particular woman's life. Early feminist writings on amniocentesis suggested it was another "male takeover" of female nature (Corea, 1985; Spallone & Skinberg, 1987). I share a general feminist suspicion of who develops and controls access to new technologies, especially in the realm of reproductive medicine, where women have served as metaphorical handmaidens and material guinea pigs to Western science throughout its history (Jordanova, 1986, 1989). But I am also suspicious of an antitechnological stance, particularly when the majority of women may still be fighting for access to some of the same biomedical technologies over which a minority has raised important criticisms. The intersecting fault lines of class, race, ethnic and religious differences, sexual preference, experiences with disabling conditions, and so forth all must influence our ongoing awareness of a need for both access and complex protections with regard to this, or any other, piece of medical technology.

Clearly, issues of gender and power weave through my current research, but their effects are multiple and never simple. I have certainly seen women pressured into the position of being "agents of quality control on the reproductive production line" by husbands (Rothman, 1986). But I have also seen women using amniocentesis above their male partner's objections. And pro-choice or anti-abortion attitudes may create schisms across gender divides within households and families. We need to locate our understandings of reproductive technologies in relation to the issues on which women might come together—the need for respectful, accessible health care; protection and expansion of reproductive rights in their full complexity. But we also need to confront the issues that potentially divide us: class-based access to differential health care, racial discrimination, and discrimination against adults and children with disabilities.

A second factor in assessing the impact of prenatal genetic
testing on women concerns the sensitivity of health care providers. Genetic counseling is a relatively new health care profession, and 95% of its practitioners are women. There are currently many "women's professions" emerging in health care, like genetic counseling, in which women speak both the languages of science and of social work, of epidemiology and of empathy. Counselors are taught to think about "psychosocial" issues using a neo-Freudian vocabulary. I am suggesting that there are also social and cultural issues at stake, and these, too, need to be discussed in the training of genetic counselors. Here, further research is certainly needed. Recently, Diana Punales-Morejon and I conducted a preliminary survey of the 15 heads of genetic counseling training programs in North America, and of 50 counselors who are particularly experienced in providing genetic services to minority and underserved populations. Our data reveal a great deal of ferment in the field over appropriate education for urban health care careers (Punales-Morejon & Rapp, 1991; Rapp, 1993a). What, for example, is the role of language training and familiarity with multicultural attitudes and aspirations toward pregnancy, testing, abortion, and childhood disability in genetic counselor training programs? We are convinced that this is a good time to build additional multicultural awareness into a small, but growing, and still-self-conscious "women's profession."

There is one additional area that should be assessed in thinking about the impact of prenatal genetic testing on women: the influence of the mass media. While this issue appears to take us far afield from health care providers and their clients, it is a critical arena in which awareness, attitudes, and values are constructed. I have been consistently impressed by the role that TV talk shows, docudramas, science programs, and soap operas play, especially in the science education of women from non-privileged backgrounds. After a Phil Donahue show featuring parent-activists of children with Down syndrome, clinic patients asked much more insightful questions about amniocentesis. The popularity of "Life Goes On" (starring a young adult with Down syndrome) has raised important issues in both the genetic services community, and among parents of children with this condition. A mother of a six-year-old with Down told
me that the single greatest weapon against the stigma her son faced was the inclusion of teenagers with Down in the McDonald's ads. Dorothy Nelkin and Susan Lindee have just completed a survey and analysis of the popular media representations of genes and genetic testing (Lindee & Nelkin, 1994). It is apparent that the density and complexity of coverage of this and related issues is expanding rapidly. A recent *New England Journal of Medicine* article suggests that doctors, too, take their citation cues from stories covered in the *New York Times* (Phillips, Kanter, Bednarczyk, & Tastad, 1991). Science writing and scientific topics have become an integral part of popular culture, for better and for worse, and like all resources in our culture, they are highly stratified and targeted. We need to know more about how stories on genetic testing and its consequences are produced and consumed. I do not intend a naive recommendation that “popular education” alone will enhance our ability to deal with the complex issues of eugenics and reproductive rights that lie at the heart of genetic testing. But surely, we need to imagine (and advocate for) greater public understandings—understandings that take place throughout all strata of our society, and that are removed from the aura of crisis so often accompanying both prenatal diagnosis and the birth of children with disabilities. Scientific literacy is a benefit and a burden affecting all whose lives are touched by reproductive genetic testing. Taking media representations and media access seriously is part of evaluating the impact of reproductive genetic testing, and reproductive technology in general, on the lives of women and their supporters.

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