

Ethnicity, Bioethics, and Prenatal Diagnosis: The Amniocentesis Decisions of Mexican-Origin Women and Their Partners

ABSTRACT

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Bioethical standards and counseling techniques that regulate prenatal diagnosis in the United States were developed at a time when the principal constituency for fetal testing was a self-selected group of White, well-informed, middle-class women. The routine use of α -fetoprotein (AFP) testing, which has become widespread since the mid-1980s, introduced new constituencies to prenatal diagnosis. These new constituencies include ethnic minority women, who, with the exception of women from certain Asian groups, refuse amniocentesis at significantly higher rates than others.

This study examines the considerations taken into account by a group of Mexican-origin women who had screened positive for AFP and were deciding whether to undergo amniocentesis. We reviewed 379 charts and interviewed 147 women and 120 partners to test a number of factors that might explain why some women accept amniocentesis and some refuse. A woman's attitudes toward doctors, medicine, and prenatal care and her assessment of the risk and uncertainty associated with the procedure were found to be most significant. Case summaries demonstrate the indeterminacy of the decision-making process. We concluded that established bioethical principles and counseling techniques need to be more sensitive to the way ethnic minority clients make their amniocentesis choices. (*Am J Public Health*. 1999;89:1658-1666)

Prenatal diagnosis is one of the oldest of the "new" reproductive technologies. From the first amniocentesis tests performed in the United States in the early 1970s, prenatal diagnosis provoked intense controversy and exposed a need for ethical standards that might govern its use. In the early 1980s, former surgeon general C. Everett Koop denounced some forms of prenatal testing as "search and destroy" missions.^{1(pixiii)} The pioneers of prenatal diagnosis took shelter from such criticism behind an ethical principle that has prevailed ever since: parents should be free to opt for prenatal diagnosis and to use the information it provides as they see fit.

This ethic of parental autonomy and self-determination was institutionalized in the form of "nondirective" genetic counseling.² Nondirective genetic counseling is meant to avoid the paternalism and prescriptivism that typifies the doctor-patient relationship. In counseling a pregnant woman or couple about prenatal diagnosis, the intended role of the medical professional is to provide information to "help individuals-couples understand their options and the present state of medical knowledge so they can make informed decisions."^{3(p549)}

At the time these guidelines and ethical standards were being established, amniocentesis was the principal diagnostic technique in use. In the process of detecting untreatable birth defects that can be averted only by abortion, amniocentesis exposes a fetus to the risk of miscarriage. Because of its risks and costs, amniocentesis was first offered only to women at high risk for fetal defects, the preponderance of whom were White, middle-class, highly educated women who had postponed pregnancy to pursue careers. The risk of bearing a fetus with some form of chromosomal abnormality rises from 1 in 450 for a 30-year-old woman to 1 in 65 for a woman aged 40 years.^{4(pp3-5)} To a large extent, the first clients for prenatal diagnosis were a self-selected group who had actively sought out the new prenatal diagnostic technologies and who were prepared to terminate the pregnancy if an anomaly was diagnosed.

The advent of maternal serum α -fetoprotein (AFP) screening in the mid-1980s has changed this situation. Unlike amniocentesis,

AFP screening is noninvasive and inexpensive, but it is sensitive to some of the most frequent birth defects, including Down syndrome and spina bifida. AFP screening therefore soon came to be recommended as the standard of care for all pregnant women.⁵ Yet, although a positive AFP result can indicate an increased likelihood of an anomaly, amniocentesis is required to confirm the problem and, if possible, identify it. Consequently, a woman who tests AFP positive is typically referred to a genetic counselor and offered amniocentesis.

Widespread AFP testing has thus introduced amniocentesis to new constituencies of women, women who had not previously considered genetic services. Among these new constituencies are women from lower- and working-class ethnic minority backgrounds, who tend to complete their childbearing at younger ages than White upper-middle-class women.^{4,6} There have been few systematic studies of how ethnicity may influence the experience of prenatal diagnosis and genetic counseling.⁷⁻⁹ But there is some evidence that ethnicity matters in prenatal diagnosis decisions. Between 1995 and 1997, the California maternal serum AFP screening program reported that 66.1% of Hispanic women and 70.5% of Black women accepted amniocentesis after testing AFP positive, compared with 75.8% of White women.¹⁰ These data are consistent with the anecdotal reports of other health care providers, which suggest that Hispanic women are less likely than women of other ethnic groups to accept amniocentesis.

Most inquiries into decision making about amniocentesis are bioethical, not empir-

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ical. Bioethics proceeds by deduction from abstract principles. Insofar as it has empirical references, these tend to be singular cases drawn from the courts or the media, which are, by definition, unrepresentative of the general population of cases. The ethical calculus that emerges from these deliberations bears little relation to how real women, faced with actual amniocentesis decisions, make their choices. Bioethics is, therefore, poorly equipped to deal with the question of how women from ethnic minority backgrounds make their amniocentesis decisions.^{11(p19)}

Few women experience prenatal diagnosis as an occasion for the exercise of moral autonomy. Prenatal diagnosis puts more information in the hands of women, but it gives them no way of acting on that information save for what is, for some, the unpalatable option of abortion. It is also possible to accept or refuse amniocentesis without experiencing it as a "decision" at all. A woman may simply accept every test that is offered, including amniocentesis, without truly registering what she is accepting. Or she may simply miss prenatal care appointments without truly registering what she is forgoing.^{12(p51)}

If bioethics tells us little about the way women in general make decisions about prenatal diagnosis, it tells us even less about the new constituencies of women faced with these decisions as a result of widespread AFP testing. Large numbers of women who screen positive now are from cultures that may not share mainstream US views about the role of medicine and prenatal care in childbearing, the meaning of disability, or the appropriate way to assess and respond to scientific risks and uncertainties. In such groups, gender ideologies and the balance of domestic power may also be quite different from the US norm. But bioethics has yet to fully recognize that this new diversity of clients may have profound implications for the way prenatal diagnosis is implemented.

What is needed, then, is empirically grounded research into the questions that bioethics neglects: How are women making amniocentesis decisions? What considerations, ethical or otherwise, are important to them? And, in the wake of the routinization of AFP testing, *who* are these women? How do their diverse ethnic and cultural backgrounds shape their experience of prenatal care and genetic services?

This article is intended as a contribution to this body of research. Our aim was to investigate how women of Mexican origin and their male partners decide whether to undergo amniocentesis (after the woman has screened AFP positive) and how they experience prenatal diagnosis and the genetic coun-

seling that accompanies it. We focused on the Mexican-origin population because it is large, young, and rapidly growing, with one of the country's highest birth rates.¹³ Women of Mexican origin (and other Hispanic women) are also at higher risk for neural tube defects than women in any other US group.¹⁴

What methodologies are appropriate for research of this kind? Given that the clients of prenatal diagnosis are now highly diverse, any empirical work needs careful measures of how far its findings are representative of the population in question. As noted above, bioethics has argued on the basis of singular, potentially unrepresentative cases. But as prenatal testing has become routine, the subject population has become large enough to allow (and require) useful quantitative work that draws statistically significant inferences from relatively large samples of cases.^{11(pp13-15)}

At the same time, it is necessary to learn something about the way decisions are made and the considerations the clients themselves consider important. These are variables that are inherently phenomenological and are discernible only to the research subject. We therefore need open-ended questions that allow women and their partners to list the considerations that are important to them rather than have to respond to answers imposed by researchers. To some extent, such self-report data may be readily amenable to aggregation and quantitative analysis. But the data will also contain valuable insights that may not be quantifiable or directly commensurable across cases. Interpretation of these results will necessarily remain case-specific, with the unit of analysis staying at the level of the individual woman or her partner, and any generalizations should be made with great caution.

We attempted to meet these diverse methodological requirements by adopting a multimethod approach. We combined the statistical analysis of data from a relatively large sample of patient charts with a content analysis of semistructured interviews and extended studies of particular cases.

From a public health perspective, the questions addressed here are significant not least because of their immediate implications for the counseling of pregnant women. New clients pose new challenges for those who counsel pregnant women. The nondirective principle they have relied on since the 1970s took hold at a time when genetic counseling's client population was small, homogeneous, and well informed about genetic services. How well do the principles of nondirective counseling translate to the new constituencies of women brought into genetic counseling by a positive AFP result?

The California Prenatal Screening Program

This research was conducted among women and their male partners enrolled in California's state-administered program for prenatal diagnosis. Since 1986, California has mandated that all pregnant women who begin prenatal care prior to their 20th week of pregnancy be offered maternal serum AFP screening. In mid-1995, total human chorionic gonadotropin and unconjugated estriol were added to AFP to improve screening for Down syndrome and trisomy 18. The screening program is financed like an insurance pool, with everyone paying a single fee (\$115 since 1995) that covers both the cost of the AFP screening, offered to all women, and the cost of subsequent services, including genetic counseling and amniocentesis, offered to the minority of women who test AFP positive. The fee is paid for by most private insurers and by California's Medicaid program, MediCal; therefore, the costs of prenatal diagnosis were rarely a consideration for the women in our sample.

Approximately three quarters of the women who are offered AFP screening accept, and 7% to 13% test positive.^{10,15-17} These women are offered a session lasting approximately 45 minutes with a licensed genetic counselor who is trained to the level of a master's degree in genetics and counseling techniques. The counseling session is intended to be nondirective²: counselors are expected to provide information and answer questions but not to make recommendations.

A high-resolution, level 2 ultrasound reveals a benign explanation (such as a miscalculation of gestational age) for about half of the AFP-positive cases as well as detecting a handful of severe birth defects, such as anencephaly and severe spina bifida. In the remaining cases, amniocentesis is the only way to confirm and identify any prenatally detectable problems. Complications from amniocentesis are uncommon but include cramping, bleeding, infection, and, on occasion, fetal injury or miscarriage. The large majority of women who undergo amniocentesis are found to have no fetal defects. When fetal defects are detected, the women are informed about any available treatments. They are also offered an abortion, which in California may be performed through the 24th week of pregnancy.

Research Questions

The principal research question motivating this study was, How do women of Mexican origin who have screened AFP positive

make decisions about amniocentesis? We looked for attitudes and sociodemographic characteristics that distinguished between women who accepted amniocentesis and those who refused. Reports from health care providers suggested that among the most significant factors are the couple's level of education, the degree to which each is acculturated to the United States, their religious affiliation and observance, and their attitudes toward abortion. We hypothesized that the more educated or acculturated a woman, the more likely she would be to accept amniocentesis. In addition, given that the religious groups most Mexican-origin women belong to (most are Catholics, Mormons, or members of fundamentalist Protestant sects) strictly prohibit abortion, we hypothesized that the more religiously observant a woman, the less likely she would be to accept amniocentesis. The degree to which a woman and her partner opposed abortion, independent of their religious convictions, was also expected to correlate with refusal of amniocentesis.

Beyond these background sociodemographic and attitudinal characteristics, we investigated the considerations the women and their male partners felt were most important in their decision making. We explored the attitudes of Mexican-origin women toward medicine in general and amniocentesis in particular. Such women may be less wedded than others to the idea that medical interventions are essential for a healthy birth. Specifically, we conjectured that women who felt confident in their ability to bear a healthy child would be more likely to refuse amniocentesis.

In a third area of study, we examined the role the male partner played in a woman's amniocentesis decisions and the influence of third parties other than doctors and counselors, such as family members and friends. Health care providers regularly explain the high rate of amniocentesis refusals among Hispanic women by citing the culture of *machismo*, whereby Hispanic men assume a high degree of authority over their wives and may refuse amniocentesis on their wives' behalf.

Finally, we investigated how the women experienced genetic counseling. Women in the interview sample and their partners were asked to rate their satisfaction with the genetic counseling they received. We also gauged whether study participants perceived their counselors as neutral or in favor of acceptance or refusal.

Methods

Data for this investigation were drawn from 2 sources: patient charts and face-to-

face interviews with a sample of women and their male partners.

Patient Chart Sample

We reviewed the patient charts of 4 genetics clinics in southern California between January 1 and December 31, 1996. For each of the 379 Spanish-surnamed women who screened AFP positive, we obtained data on sociodemographic characteristics, reproductive and family history, AFP screening results, and the amniocentesis decision. The patient chart sample was relatively large, and because the data were collected anonymously, the sample was not biased toward patients who were willing to give informed consent. Properly coded, the data on each of these variables were suitable for calculating a range of descriptive statistics and significance tests.

The patient charts allowed us to relate each patient's sociodemographic characteristics and reproductive history to the result of her amniocentesis decision. The data tell us nothing, however, about the decision-making process. To explain the decision-making process, self-report data are necessary.

Interview Sample

Our semistructured interviews provided this self-report data. Between 1995 and 1997, we conducted semistructured, face-to-face interviews with 2 waves of eligible women of Mexican origin. Participants were recruited from 6 southern California state-approved prenatal diagnosis centers. For the pilot phase, we recruited an opportunistic sample of 25 couples. In the main phase of the research, 991 potential participants were screened, and the 122 women who fit the study's criteria (Mexican-origin women with Hispanic partners who had been offered amniocentesis after a positive AFP result) were included in the interview sample. Thus we used interview data from 147 women and 120 men (interviews with the remaining 27 men could not be scheduled for various reasons). The interviews gave us information on a wide range of variables mentioned by the women themselves, including phenomenological variables that had a bearing on the process, not merely the result, of their decision making.

Questions explored in the pilot study were evaluated and the most reliable, comprehensible, and informative questions were incorporated into a semistructured interview guide. The order of questions remained largely the same in each interview, but interviewers followed up on topics that the respondents themselves raised. Where necessary, standardized probes were used to seek further information or clarification.

The interviews were conducted after the women had made their amniocentesis decisions, but some were still awaiting their amniocentesis results. Interviewing the woman and her male partner together proved worthwhile in the pilot survey, and joint interviews were conducted with the 49% of couples who requested them. Sixty-nine percent of the participants chose to be interviewed in Spanish and 31% in English. Interviews were generally conducted in participants' homes; some follow-up interviews were conducted by telephone.

Many of the interview questions were coded quantitatively to allow us to make statistically significant inferences about phenomenological variables that are difficult to measure. The interview results reported here are based on the combined responses of the pilot and main samples. Many of the questions were also coded qualitatively, with all responses to a single question or topic analyzed for content and patterns.¹⁸

We have included several summaries of the interviews of individual women. Not only do these case summaries provide texture, nuance, and detail, but they also change the unit of analysis from the particular interview question to the individual interviewee. They therefore address some of the blind spots of quantitative coding.

Our qualitative content analysis focuses on the considerations that women found pivotal in choosing whether or not to accept amniocentesis. This analysis focuses less on the turmoil and conflict some women felt than on how their conflict was resolved. The women were asked to account for their decisions, not to articulate their dilemmas. The case summaries provide examples of the way internal conflicts were played out.

As previous research has shown,^{12,19} not all women experience their amniocentesis choice as a dilemma or even as a conscious decision. Content analysis considers the factors that entered into a decision in isolation from the decision maker. Consequently, content analysis does not distinguish effectively between women who wrestled with a number of competing factors in making their decision and women for whom the choice was straightforward. The individual case summaries illustrate their differences more clearly.

Results

Some sociodemographic characteristics of the interview sample are shown in Table 1. With regard to reproductive history, the women in the sample reported an average of 2.01 previous pregnancies (range = 0–8; SD = 1.94). Forty-six (31.3%) of these

women reported having had miscarriages; 34 (73.9%) reported only 1 miscarriage and the rest 2 to 4. Twenty-five (17.9%) of 140 women reported having had 1 or more induced abortions; 21 (84.0%) reported 1 such procedure and the others 2 or 3. Fifteen (10.3%) of 145 said they had had children who died (13 reported 1 such child and 2 reported 2), and 10 (6.9%) of 144 said they had children who were born with anomalies (n 's < 147 owing to missing data). There were no statistically significant differences in reproductive history between the interview sample and the more randomly drawn chart sample.

Sixty percent of the women in the interview sample accepted amniocentesis and 40% declined, a refusal rate significantly higher than in most other US populations.¹⁰ All but 2 of the amniocenteses were negative. Both women who tested positive opted for abortion. In addition, the level 2 ultrasounds of 2 women who refused amniocentesis indicated the likelihood of problems. One miscarried; the other gave birth to a baby with multiple anomalies.

The sociodemographic variables and reproductive histories abstracted from the patient charts were found to have little explanatory power. Few sociodemographic factors differentiated those who accepted amniocentesis from those who declined. We found no significant differences in age or educational background for either sex, and no significant differences in household income. Both groups of women had similar reproductive histories, and there was no difference in family histories of birth defects.

We had hypothesized that men and women who were less acculturated to the United States would be more likely to decline amniocentesis. This hypothesis received partial support. Women born in Mexico were significantly more likely than women born in the United States to refuse amniocentesis ($\chi^2 = 4.67, P = .031$), but neither scores on a standardized acculturation instrument²⁰ nor length of time in the United States, for immigrants, was predictive. For men, neither birth-place nor acculturation score was associated with amniocentesis decisions.

We had anticipated that more religiously observant Catholics would be more likely to decline amniocentesis because of the Church's strict opposition to abortion. The sample was overwhelmingly (83%) Catholic, but neither those who accepted nor those who declined were particularly observant. Only 16% reported attending Mass every Sunday, and just 13% regularly went to confession and took communion. Neither women's nor men's religious background and practice were associated with amniocentesis decision.

TABLE 1—Characteristics of Mexican-Origin Women and Their Male Partners Interviewed About Their Amniocentesis Decisions: Southern California, 1995–1997

	Women (n = 147)		Men (n = 120)	
	No.	%	No.	%
Ethnicity^a				
Mexican American	45	30.6	34	28.3
Mexican immigrant	102	69.4	76	63.3
Other Hispanic	0	0	10	8.3
Education				
≤6 y	37	25.3	31	26.7
7–9 y	72	49.3	60	51.7
≥10 y	37	25.3	25	21.6
Household income, \$/y				
<10 000	49	34.5	34	28.8
10 001–20 000	42	29.6	43	36.4
>20 000	39	27.5	34	28.8
Don't know	12	8.5	7	5.9
Religion				
Catholic	125	85.0	96	80.0
Other	15	10.2	10	8.3
None	7	4.8	14	11.7

Note. Numbers add up to fewer than 147 (women) and 120 (men) because of missing data.

^a"Mexican American" was defined as having been born in the United States or having immigrated before completing primary school, "Mexican immigrant" as having immigrated after completing primary school, and "other" as from a Hispanic background other than Mexican.

Although women who declined amniocentesis were significantly more likely than those who accepted to describe themselves as strictly opposed to abortion ($\chi^2 = 13.99, P = .007$), there was significant overlap between the 2 groups of women in their views on abortion. Just over half (53.4%) of those who accepted amniocentesis said they would ever consider having an abortion, as did 26% of those who declined. Moreover, fully 42% of those who agreed to undergo amniocentesis said they felt that abortion was personally unacceptable under all circumstances. (Two thirds of women who refused also held this view.) There was no association between the male partners' views on abortion and the women's decisions about amniocentesis.

During the pilot phase of the research, we asked interview subjects to describe all of the considerations that contributed to their decision; we probed until we were satisfied that no additional factors had been considered. This exercise resulted in a list of 30 reported reasons for refusing or accepting amniocentesis. We then asked participants in the main study to rate, on a 4-point scale (0–3), the importance of each of these factors in their own decision. We performed *t* tests and found statistically significant differences ($P < .001$) between those who accepted and those who declined for two thirds of the reasons (Table 2). Spouses

reported similar but not identical reasons for their decisions.

Some of the strongest differences between those who accepted and those who refused were found in their attitudes toward doctors, medicine, and science. Those who accepted were more likely to indicate that physicians' recommendations were an important factor in their decision. They were also more likely to believe that a negative amniocentesis result would resolve uncertainty and provide reassurance, while a positive result would provide doctors with helpful information. By contrast, those who refused were more skeptical about the accuracy and value of scientific information and reported a higher degree of discomfort with technology, machines, and needles. They were much more likely than those who accepted to believe that their fetus was healthy, despite the positive AFP test result. The 2 groups were similar in their belief that their decision was best for the baby and that God would help them regardless of the outcome.

It is common for any woman and her partner to be anxious about the prospect of amniocentesis, but these anxieties seemed especially strong in our study population. Many found the idea of amniocentesis frightening. Even after genetic counseling, several concluded that amniocentesis is "like a small operation." Sixty-two percent described the

TABLE 2—Importance of Various Factors in Mexican-Origin Women's Decision to Refuse or Accept Amniocentesis: Southern California, 1995–1997

	Mean		<i>t</i>	<i>P</i>
	Refusers	Acceptors		
Reassurance	0.54	2.58	-12.51	0.000
Doctor's advice	0.33	1.77	-9.04	0.000
Fear of miscarriage	2.52	0.94	9.05	0.000
Amniocentesis against God's will	0.83	0.18	4.04	0.000
Faith in God's help	2.11	1.52	2.85	0.005
To be prepared	0.40	2.50	-13.92	0.000
"For the good of the baby"	2.35	2.64	-1.98	0.051
Will rely on prayer if there is a problem	0.60	1.22	-3.57	0.001
Difficulty in conceiving	0.58	0.20	2.54	0.013
Previous experience with amniocentesis	0.07	0.22	-1.52	0.132
"I feel the baby's fine"	1.44	0.55	4.57	0.000
Last or only chance to be a mother	0.72	0.40	1.79	0.077
Child is wanted regardless of health	2.21	0.88	6.74	0.000
"Pro-life" position	1.37	0.45	4.25	0.000
Amniocentesis suggested, not recommended	0.46	0.39	0.45	0.657
Fear of machines or needles	1.41	0.80	3.64	0.000
"Don't want to know"	0.96	0.33	3.57	0.001
Fear of spouse's insistence on abortion if there is a problem	0.22	0.26	-1.20	0.234
Test cannot cure a problem if detected	1.42	0.60	4.58	0.000
Test may be wrong	1.39	0.52	4.89	0.000
"We're in good health"	1.36	0.66	3.36	0.001
Wish to abort if there is a problem	0.15	1.59	-7.82	0.000
Amniocentesis can harm the mother	0.81	0.35	3.73	0.000
Amniocentesis can harm the fetus	2.42	0.89	9.30	0.000
Will feel guilty if test results in miscarriage	1.91	0.64	6.69	0.000
So doctors can help the fetus	0.45	1.31	-5.29	0.000
Knowledge of a problem may result in temptation to abort	0.36	0.69	-1.49	0.138
Fear of inherited illness	0.16	0.44	-0.92	0.362
First child	0.51	0.62	0.58	0.564
Amniocentesis recommended by a respected person	0.42	0.47	0.43	0.670

^aImportance was rated on a 4-point scale: 0 = not at all important; 1 = a little important; 2 = quite important; 3 = very important.

procedure as "rather" or "extremely" risky for the fetus; 22% described it as "rather" or "extremely" risky for the mother. Several men and women refused in part because they feared that the woman could die or suffer severe complications. These negative views of amniocentesis were far stronger among those who refused than among those who accepted. Those who declined rated the procedure as significantly more risky than those who accepted ($t=9.28, P<.001$) and said that fear of miscarriage was a significant factor in their decision to decline ($t=8.77, P<.001$).

Male Partners' Role in Amniocentesis Decision Making

On the basis of reports by health care providers, we had hypothesized that these women's male partners would play an important role in their amniocentesis decisions, particularly among less acculturated women. This hypothesis was not supported by our findings. Of the 120 couples interviewed, 51% of both women and men said that the

woman had made the decision; 24% said it was a joint decision. Only 14% of the women indicated that their partner's opinion counted more than their own. The remaining 11% said that someone else (e.g., parents, in-laws, siblings, a clinician) made the decision. As expected, the least acculturated men and women said that the man's opinion had counted most, but this pattern was not very strong (NS).

Moreover, even when the decision was a joint one, the woman's opinion generally carried more weight. While many men were actively involved in their wives' pregnancies (e.g., attending prenatal consultations, anticipating being present at the delivery), both sexes regarded the man's role as that of a supportive helper in pregnancy rather than as an equal partner. They agreed that the woman should have the final word in the amniocentesis decision because it was her body that would be tested, or because her previous reproductive experiences and knowledge made her more qualified to decide. Although these findings contradict common assump-

tions about the culture of *machismo*, this view of men's supporting rather than controlling women's reproductive behavior is consistent with the "separate spheres" model of gender organization that is fundamental to Hispanic societies: women are considered responsible for all family-related matters, men for public and economic activities.²¹

Genetic Counseling Experience

For the most part, participants reported very favorable reactions to the genetic counseling they received; the mean satisfaction rating was 8.5 out of 10 for women and 8.6 for male partners who attended the counseling sessions. Not surprisingly, perhaps, those who accepted amniocentesis gave the counseling higher ratings than those who declined ($t=-2.94, P=.004$). Only 12% of the entire sample said they felt pressured by their counselors to accept amniocentesis, while 32% said they would have liked their counselors to be more directive, or at least more explicit about their own opinion of the value of fetal diagnostic technologies.

At the same time, probing revealed that many participants were uncomfortable with what they felt to be the counselor's implicit pressure to agree to amniocentesis. For instance, several said they would have preferred that the counselor terminate the session as soon as they declined the amniocentesis offer. Instead, the counselors continued until they had completed their protocols, often asking the women several more times if they were sure they did not want the procedure. This type of counseling sometimes heightened the women's ambivalence and led them into a protracted period of indecision before they settled on a final course of action.

Case Summaries

The case summaries illustrate how the individual factors analyzed above can play out in different ways during the process of decision making. Laura and Dolores both refused amniocentesis, but they went through quite different decision-making processes. The same is true for Maricarmen and Clara, both of whom accepted amniocentesis. Moreover, women who ultimately came to different decisions about the procedure, such as Dolores and Clara, expressed similar fears, concerns, and attitudes.

Maricarmen: accepted, without difficulty. Maricarmen was 34 when she was interviewed and was pregnant with her fourth child. Her reproductive history had been uneventful. She was born and raised in Hidalgo, Mexico, where she received a pri-

mary school education. In 1978, a sister who was living and working in California persuaded Maricarmen to come to the United States. Her husband, Manuel, joined her 2 years later. He was from the same small village as she, and once in the United States found intermittent work in construction. Maricarmen had worked in a restaurant until she began having children; since then she had worked as an occasional domestic laborer.

Both Maricarmen and Manuel expressed marked deference toward medical authority. Maricarmen believed that medical professionals would not suggest a test without reason or make a mistake. "Not in this," she explained, "because it's with blood and machines. . . . That's what the machines are for." She would even accept the doctors' advice if they suggested abortion. When asked if she had agreed to amniocentesis so that she would not feel guilty if something was, in fact, wrong with the baby, she said, "Yes, I'm going to do everything the doctor says. I'm going to ask that they do *all* the analyses."

Maricarmen was motivated to have amniocentesis by her fear of giving birth to a child with Down syndrome. "This is what I worry about most, that it will be born mongoloid." Maricarmen had strong attitudes about specific disabilities. She was not concerned about heart disease or deafness, but she was greatly concerned about blindness, mental problems, physical disfigurement, paralysis, epilepsy, and cleft palate. She said she would abort if she knew her child would be sterile: "What's a boy who can't do this going to be? [Such a] person is incomplete."

Maricarmen had already had an induced abortion for financial reasons, and she said she would have another if the amniocentesis detected a problem. She said she was not religious and did not necessarily hold to the Catholic doctrine that life begins before birth; however, she did believe that praying can help change a person's luck. Maricarmen had found it difficult to wait 2 weeks for the test results, and her husband had not been very supportive during that time because he was preoccupied with his chronically uncertain employment situation.

Laura: refused, with conviction. Laura was 29 years old and had come to the United States from Mexico with her parents when she was 6. They had been peasant farmers in rural Jalisco and continued to do agricultural work in the United States. Laura was working in a grocery store at the time of the study; her husband, who was born in the United States, worked as a parking lot attendant. This was Laura's third pregnancy; her first 2 children had been born without problems.

Laura was skeptical about her positive AFP result, because a coworker had previously

suffered a false-positive result: "She was very worried and crying . . . thinking the baby was going to be born sick, and the baby was born just fine." Laura reasoned that since she would have the baby in any event, there was no point in going through the anxiety of amniocentesis. She believed in the value of knowledge for its own sake, but in this case, she said, the knowledge was not worth the potential cost. "What if my baby was fine, but I'm one of those that loses it [as a result of the amniocentesis]? No, no, no. I would feel guilty for what I did." She knew of no hereditary disorders in her own or her husband's family and was confident that the baby would be healthy.

Laura said that the genetic counseling session met her needs but that it was, to some extent, redundant. "The truth is that I didn't even want to go because in any event I was going to have the baby. I had already read some booklets, the ones they offer in the event that AFP comes out high or low. So I had in my mind decided not to do it [have the amniocentesis]." She said she was not opposed to abortion for other women, in the case of rape, for instance, or even for herself if it were necessary. But in this case, "I want to have a baby, and if it's fine or if it's sick I'm going to have it."

Laura described the decision as hers. "Nearly always in things like this, I'm the one that makes the decisions because it's my body." She was separated from her husband and did not give him any details about the test. Her boss and her sisters gave her advice and support. She also talked with her 12-year-old son: "I told him there was the possibility that the child would be born sick and he said, 'It's better to have it.' And I said, 'It wouldn't bother you if it was born sick, you'd love it?' And he said, 'Of course. It's going to be my brother.' And this gave me more security."

Although the couple was separated, Laura's husband, Xavier, supported her decision. He was opposed to abortion; if there had been a problem with the baby, he would have "accepted what God had sent." When asked why they refused the amniocentesis, he said, "Because she didn't want it, and I believe that everything will be fine because we are healthy."

Clara: accepted, with difficulty. Clara was born in 1977 and had been in the United States 10 years. She worked as a hairdresser. Mario, her husband, came to the United States when he was 20 hoping to find stable employment; although his father was a schoolteacher, Mario did not finish high school. Instead he had apprenticed himself to an auto mechanic. Clara had miscarried twice in the past. She particularly wanted this child because problems in her marriage meant this might be the only child she would have.

Clara accepted the AFP test hoping for reassurance: "I wanted to do it. I thought they would be able to tell me that everything was fine and then I could relax and finish the pregnancy." The AFP test results were positive and the ultrasound was inconclusive, requiring amniocentesis to determine whether there was a problem.

Work prevented Clara's husband from attending the genetic counseling session. The discussion of possible defects at the session left a powerful impression on Clara. "They said the baby could come with an enormous head, that it could come with dead legs. . . . I was terrified to think about all these things." Clara was afraid both of the defects the amniocentesis might detect and of the amniocentesis procedure itself. The amniocentesis could have been performed that day, but Clara needed time to think through her decision. She told the hospital she needed to talk it over with her husband. "I didn't want [the amniocentesis] but on the other side I wanted to. . . . I was afraid of everything they told me [about] if I didn't do it . . . and I was afraid to do it. . . . I wanted to go and think before saying yes or no."

Clara thought that if she refused amniocentesis she might offend her physician, who recommended the procedure in hopes of understanding what had caused her previous miscarriages. "I didn't want her to think I didn't have faith in her. I have a lot of faith in my doctor." She was less satisfied with the genetic consultation. She detected implicit pressure in favor of the test. "They say one can say yes or no but I believe that they want you to do it. . . . First I said no, I don't want to do it, but [the counselor] said, 'There is very little risk, very little pain, it's like having an injection.' . . . It seems to me that if I had refused the test they would have said, 'Oh, this woman is ignorant, she knows nothing.'"

When asked what made her decide in the end to accept the amniocentesis, she replied, "To tell you the truth, I think it was the fear. I think that the people there put a fear into you. I was so afraid, I thought better to end this. . . . I wanted to know because not knowing is terrifying." She also wanted to feel that she was doing everything she could to help ensure a healthy birth. "If it came [with severe birth defects] and I hadn't done the tests I would think, well, I didn't do everything that they told me and for not doing everything, now I have to pay."

Clara's husband said that he wanted her to have the test and he would want her to have an abortion if the fetus were found to have birth defects. "In my situation now it's impossible to raise a sick child, and if I can't, no one else will. Abortion might be painful

but you can't bring a child into the world to suffer." Clara would not condemn abortion for others—she saw it as a “very personal thing”—but she did not anticipate aborting this pregnancy. “I wanted to know but not to end the pregnancy, nothing like that. This pregnancy cost me a lot. Because before I lost 2 . . . I said, ‘My God, let it be born healthy, let all be perfect. If it's sick, I'll also accept it . . . because I want to accept what you send me.’”

Dolores: refused, on the advice of a third party. Dolores, aged 25, had been in the United States just 2 years. Her husband, Martin, had immigrated several years earlier and finally felt secure enough economically to send for her and their daughters. Although her father was a brick maker and her mother was a laundress, Dolores had gone to secretarial school and was more educated than many women in the sample. This was her fourth pregnancy. She had 2 daughters, aged 6 and 3 years, and had recently suffered a miscarriage.

Dolores admitted, somewhat reluctantly, that she had refused the amniocentesis on the advice of a fortuneteller, a friend of the family, who had told her that she had tested AFP positive because she was being bewitched by one of her husband's former girlfriends. The fortuneteller told her not to accept any invasive medical procedures and to minimize the threat to the pregnancy by resting, remaining in the house, and not accepting visitors. Dolores was also afraid of the risk of miscarriage associated with amniocentesis, especially because she had miscarried before. “They themselves said you could lose your baby, and it was very hard for me to get pregnant. I lost one already and I don't want to lose this one too.” Martin would have liked to know for sure whether there were problems with the fetus, but he deferred to the advice of the fortuneteller. “If she's being bewitched, then it's better not to do the test.”

Martin could not afford to miss work to accompany Dolores to the genetic counseling session. Dolores believed the counselor wanted her to accept amniocentesis, but the counselor had little credibility for Dolores, because she did not believe that Dolores had been bewitched. Dolores even turned down the noninvasive ultrasound, because “if I'm already in the testing room, later they'll want me to do the other one and I won't be able to get out of there.” When asked why Dolores went to the hospital for the counseling session at all, Martin explained that she went “to comply with what the doctors ordered, because once the baby is born she will go there. It's better not to miss appointments.” Martin was concerned that the doctors would

think they were ignorant for turning down the test.

Dolores saw the value of foreknowledge. “Sometimes you can change luck, other times no, it's fixed. But it's clearly better to know, even if you can't change it.” But she also recognized that worrying about the uncertain prognoses of medical science takes a toll. When asked if she saw any benefit in preparing for possible problems, she replied, “No. In fact, I think it's the reverse. I see that you can be bitter all the time and what for? . . . Because I have heard of a thousand cases of [the doctors] saying one thing and another thing comes out.”

Martin and Dolores were both against abortion in most circumstances. “In my country they'll put you in jail if you do something like that,” Dolores said. Both could envision circumstances in which abortion might be unavoidable, for example, if the pregnancy endangered the life of a mother who already had a child she must care for. In the case of a fetus with serious birth defects, Dolores said, “I believe that if the mother is strong—I, for example, I could care for it, I could have it. But there are mothers who are weak. In that case [an abortion] would be for the good of the baby. Better not to bring it into the world to be tossed about from one side to another.”

Discussion

The case summaries illustrate some of the general limitations of our more quantitative patient chart data. The patient charts allowed us to test, *inter alia*, whether reproductive history helps determine a woman's amniocentesis decision. But the case summaries show that the facts of a woman's reproductive history can weigh in on either side of the amniocentesis dilemma. A woman who has miscarried in the past may accept amniocentesis to find out whether similar problems will occur with her current pregnancy, or she may be so concerned about losing this pregnancy that she refuses to run the risks associated with amniocentesis. Compare the cases of Clara, whose doctor felt amniocentesis would provide reassurance after her 2 previous miscarriages, and Dolores, who refused amniocentesis partly out of fear that it would cause a repeat of her earlier miscarriage. These 2 cases illustrate that it is not always the bald facts that count in an amniocentesis decision, but the way those facts are apprehended by the woman. Hence self-report data, whatever their limitations, are indispensable.

The Burden of Unwanted Decision Making

Prenatal testing is offered to women in observance of their right to choose. However, women do not universally welcome the choice prenatal diagnosis offers them. According to some commentators, the offer of prenatal diagnosis confers on women “the burden of unwanted decision making.”^{3(p542)} Write Kolker and Burke,

Even those who refuse testing—for example, women who would not consider aborting a defective fetus and those who would rather not subject their pregnancies to what they deem hazardous and unnecessary interventions—must confront the decision. They must make their reasons for declining explicit and convincing to themselves, their partners, their health care givers, and sometimes to strangers.^{4(p5)}

This argument holds, *a fortiori*, for the new constituencies of women introduced to amniocentesis through routinized AFP testing. The original clients of prenatal diagnosis, who were at risk because of their advanced maternal age, embraced the tests, seeking reassurance. Many of the women who now test AFP positive, however, were fully confident of their ability to bear a healthy child before they received the AFP result. For these women, the AFP test and the offer of amniocentesis are as much a cause of doubt and anxiety as a source of reassurance.

Unprepared for the offer of amniocentesis, many women in our sample were unsure how to respond. Ultimately, accepting the amniocentesis may be the only way to resolve the worry and doubt that the offer of amniocentesis has itself precipitated. Clara, for example, explained, “I realized I had to do [the amniocentesis] because if not, I would have gone crazy with the terrible things I had in my head. . . . I wanted to know because not knowing is terrifying.” Among the women in our sample who refused, there were those who had never wanted amniocentesis but had nonetheless felt pushed into a protracted, wrenching dilemma by genetic counselors who did not take the first no for an answer. Worried by the AFP result, but having refused amniocentesis, many actively pursued alternative courses of action, such as praying, taking traditional remedies, and avoiding stress, to assuage their fears and help them feel as though they were doing everything they could to ensure a healthy pregnancy (C.H. Browner and H.M. Preloran, unpublished observations, 1995–1997).

The “burden of unwanted decision making” includes the burden of taking responsibility for whatever one decides. An important part of accounting for a decision is justifying it to others and avoiding blame for oneself: as

well as being “explicit and convincing,” one’s reasons must be beyond reproach. Fear of being blamed for a course of action can interfere with a strictly rational judgment. The more risky but blameless option can become preferable to the less risky option to which blame can be attached. This thought process enters into both refusals and acceptances. Laura rejected amniocentesis because she feared feeling guilty if it caused a miscarriage; Clara accepted because she feared she would be culpable if the baby were born with a defect.

Genetic Counseling of Mexican-Origin Women and Their Partners

Does genetic counseling help women manage the burdens of amniocentesis decision making? How well does the nondirective principle, originally developed for use among a class of well-prepared, self-selected women, translate to new groups of women who are unprepared to make amniocentesis decisions?

Genetic counseling received high marks on average from the women in our sample, but it is clear that it was not wholly successful in bridging the imposing gulf “between science and social experience.”^{22(p107)} Both those who accepted and those who refused showed signs of misunderstanding prenatal diagnostic technologies and the birth defects they detect. As noted above, those who refused tended to mischaracterize amniocentesis as “a small operation” and exaggerate its risks. Sixty-two percent described the procedure as “rather” or “extremely” risky for the fetus. In fact, miscarriage rates at the hospitals participating in the study ranged from 1 per 500 amniocentesis procedures to 1 per 200 (C.H. Browner and H.M. Preloran, unpublished data, 1996).

If the risks of amniocentesis were overstated, our case summaries show that the risks of birth defects were also exaggerated in the minds of many women. There are a large number of possible abnormalities that could trigger a positive AFP result, but the probability of occurrence is relatively small. In our sample of 147 women, all of whom had tested AFP positive, only 4 (2.7%) actually had fetuses with birth defects. It may be that women register the sheer number of possible defects, some of which can be disturbing to contemplate, without registering how small the chances of occurrence are. Asked if she remembered the defects discussed in the genetic counseling session, Clara seemed overwhelmed by the number of problems mentioned. “They said the baby could come with an enormous head, that it could come with dead legs. . . . I was terrified to think about all these things.”

A common misunderstanding evident among those who accepted amniocentesis was the assumption that only one of the options available to them—acceptance of the procedure—was sanctioned by medical science. People are accustomed to paternalism in their relationships with medical professionals; they expect “doctor’s orders,” prescriptions, and reassurances. Nondirective counseling is alien to most people’s experience of medicine. A large proportion (32%) of the sample said they would have liked their counselor to be more directive, as if the counselor could have told them what would be best for them.

When, against expectations, the counselors refrained from prescribing a course of action, many women scrutinized their counselors, looking for implicit cues as to what they should do. These cues were often forthcoming. As Clara explained, “First I said no, I don’t want to do it, but [the counselor] said, ‘There is very little risk, very little pain, it’s like having an injection.’” And it is not only the doctor’s (or the counselor’s) medical opinion that counts. Among the more powerful reasons for considering amniocentesis reported by many in the sample, including Clara and Martin (Dolores’ husband), were the desire to maintain good relations with the medical staff, who would ultimately help them through childbirth, and the wish to avoid being thought ignorant.

These implicit cues, whether real or perceived, explain why many cited their doctor’s opinion as decisive, although only 12% reported any pressure from medical personnel. Indeed, among the women who strictly opposed abortion, a principal explanatory factor distinguishing those who accepted from those who declined was the degree to which they deferred to medical authority. Contrary to the principles of nondirective counseling, the “locus of control” for these women lay with medical professionals.

Conclusion

The bioethical debate on prenatal diagnosis, animated by abstract principles and untamed by fact, oscillates between extremes—between those who vilify the techniques and those who support them uncritically. Both sides of the debate translate their convictions about abortion into convictions about prenatal diagnosis. Most of those who support a woman’s right to choose abortion argue from the same principle that a woman has the right to choose prenatal diagnosis. Those who oppose abortion, or who oppose termination of a wanted pregnancy for genetic reasons, see

prenatal diagnosis simply as the handmaiden of abortion and the harbinger of an imminent eugenics.

This investigation, relying not on bioethical principles but on empirical research, shows that neither of these positions is representative of Mexican-origin women faced with actual amniocentesis decisions. These women’s attitudes toward abortion are not the deciding factors. Their prime concerns are to do what is best to ensure a healthy pregnancy and to resolve uncertainty, but, as our case summaries show, these concerns can lead women to opposite decisions on amniocentesis. Prenatal diagnosis offers no right answers.

What conclusions can be drawn from this study for prenatal diagnosis programs and health care providers? Two dangers are evident.

Health care providers have a tendency to assume that Hispanic women’s decisions are governed by deep-rooted, cultural givens—such as religion, *machismo*, or opposition to abortion—that are nonnegotiable and beyond the influence of doctors, counselors, or medical norms. A nondirective counseling session, in which a woman is supposed to weigh her options in the light of medical knowledge and come to an autonomous, rational choice, would seem redundant for women whose decisions have already been made for them by their culture. As we have shown, this assumption is a misreading of such women’s motives. Religion, *machismo*, and attitudes toward abortion are far from being the deciding factors in their amniocentesis decisions. In fact, our findings suggest that the most important factors include the women’s understanding of the risks of amniocentesis, their fear of birth defects, their faith in medicine, and their relationships with their doctors. There is the danger that health care professionals, blinded by a complacent belief in ethnic determinism, will neglect these more subtle influences on Hispanic women’s amniocentesis decisions. As a consequence health care professionals will remain insensitive to the way Hispanic women’s decisions can and do fall prey to misunderstandings, exaggerated fears or faith, and a misplaced concern about maintaining good relations with medical professionals.

Prenatal diagnosis programs such as California’s universal AFP screening program operate on the principle that a woman’s right to make informed decisions about her pregnancy entitles her to the information that fetal testing provides. Some women in our sample wanted this information and were prepared to act on it. But there were others on whom this knowledge and the expectation of self-determination imposed a heavy psycho-

logical cost. There is a danger that as AFP testing becomes routine, women of both types will accept it automatically and the potential psychological costs of prenatal diagnosis will not be considered until after the event. Hence, most of the women in this study, who were not well informed about genetic services, found themselves plunged unprepared into a fraught decision about the future of their pregnancy. At some point, the right not to know—the right to trust in one's own ability to bear a healthy child—was surrendered, but the moment of surrender was not made clear at the time. □

Acknowledgments

This research was supported in part by UC-MEXUS, the UCLA Center for the Study of Women, and the National Center for Human Genome Research (1R01 HG001384-01), and by the Russell Sage Foundation, where Dr Browner was a visiting fellow in 1998 and 1999. The support of each of these institutions is gratefully acknowledged.

Maria Christina Casado, Irma Herrera, Carolina Izquierdo, Nancy Monterrosa, Jesus Montoya, Jeffrey McNairy, and Ricardo Rivera helped with the interviews. Casado, Monterrosa, and Rivera also assisted with preliminary data analysis. Ann Walker, director of genetic counseling at the University of California, Irvine, and Elizabeth Billings of the Indiana University Prenatal Diagnosis Center generously made unpublished data available. Permission was obtained from the institutional review board of each participating genetics clinic, and interviewees signed consent forms.

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