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Interpreting Low-Income Latinas' Amniocentesis Refusals

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As with other medical care, low-income Latinas turn down prenatal genetics services, including amniocentesis, more than any other U.S. group. Amniocentesis is a medical procedure that provides information about a fetus' health. Virtually all conditions the test detects are untreatable other than by induced abortion. Because little is known about why Latinas accept or decline amniocentesis and the role ethnicity might play in their decision, we sought to address these issues. We first identify factors associated with amniocentesis acceptance and refusal in a group of Mexican-origin women. We then described the actions those who refused took after turning down the test and their explanations for their acts. We show that while study participants' ideas about what put their pregnancies at risk were often at odds with those of clinicians, their objectives were similar: to reduce risk and maintain hope in the face of uncertainty.

The advent of alpha fetoprotein (AFP) screening marked a new chapter in the development of fetal diagnosis. Unlike amniocentesis, which because of its cost and risk of miscarriage is offered only to women at increased risk of bearing a child with a birth defect, AFP screening—inexpensive and with no medical risk—is recommended for all pregnant women. As a screening test, however, AFP provides no diagnostic information, but women who screen AFP positive are offered amniocentesis in an effort to determine why. Few U.S. women turn down AFP testing (Cunningham, 1998; Greenberg, 1988). Providers tend to encourage it, feeling the test is in their patients' best interests, and pregnant women look forward to the reassurance they anticipate a

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normal result will provide. Many pregnant women, in fact, consider AFP screening a routine part of their prenatal care (Browner & Press, 1995; Jorgensen, 1995; Lippman, 1994; Rapp, 1993b). In reality, however, a significant proportion of women screen positive, meaning that something may be wrong with the pregnancy. These women find themselves embarking on a far less routine course of events that inevitably involves further testing and for many, weeks of heightened anxiety (J. Green, 1990). About half of the women who screen AFP positive are offered amniocentesis. In contrast with the generally casual way most women assent to AFP testing, amniocentesis decisions are typically deliberate and far more complex.

Until now, most research on amniocentesis decisions has been done with women at high risk for a defective pregnancy due to maternal age, family history, or personal reproductive history (e.g., previous birth of a child with an anomaly, multiple miscarriages). Most work has been with women who agreed to the procedure (Adler, Keyes, & Robertson, 1991). Much of what we know, then, about women's amniocentesis decisions and experiences comes from a self-selected population of women who are already concerned about their ability to bear a healthy child. Moreover, the participants in these studies have overwhelmingly been middle class, urban, well-educated, and European or Euro-American (Kolker & Burke, 1994; Nsiah-Jefferson, 1993; Rapp, 1993a, 1993c).

Nevertheless, some consistent patterns emerge from the sparse literature that compares women who agree to amniocentesis with those who decline. Researchers have found a positive association between socioeconomic status and amniocentesis acceptance. For instance, Metheny, Holzman, Taylor, Young, and Higgins's (1988) survey of all Michigan women over 40 who gave birth to a live-born child in 1981 found that those who turned down amniocentesis tended to have fewer years of schooling and were less likely to have medical insurance. Two California studies confirm an association between socioeconomic status and use of amniocentesis (Duster, 1990, pp. 63-65; Golbus, Loughman, Epstein, Halbasch, Stephens, & Hall, 1979).

Certain attitudinal factors also predict amniocentesis refusal, specifically a negative attitude toward abortion, a stronger belief that the fetus is in good health, and a fear that the fetus would be injured by the procedure (Julian-Reynier et al., 1994; Marteau et al., 1991; Scholz, Endres, & Murken 1990). Other research finds that amniocentesis decisions are affected by religious attitudes but not completely determined by them (Seals, Ekwo, Williamson, & Hanson, 1985). Moreover, a negative attitude by a woman's physician toward fetal diagnosis has also been associated with amniocentesis refusal (Julian-Reynier et al., 1994).

The routinization of AFP testing, however, has considerably broadened the universe of women offered amniocentesis to a much more diverse population at no prior risk for a defective pregnancy. Far less is known about what prenatal testing in general, and amniocentesis in particular, means to these low-risk women who typically enter pregnancy with no plans for fetal diagnosis and no idea they will be offered it (Evans et al., 1987). Many also come from ethnic minority backgrounds. Studies consistently show that amniocentesis acceptance rates following a positive AFP test vary by geographical region, social class, education, race, ethnicity, and acculturation (Cunningham, 1998; Haddow et al., 1992; Kuppermann, Gates, & Washington, 1996; Marfatia, Punaless-Morejon, & Rapp, 1990; Marion et al., 1980; Marriott, Pelz, & Junze, 1990; Press & Browner, 1998; Tr an, 1998). For instance, although about 80% of Euro-American women offered amniocentesis following a positive AFP agree to it, only about 50% of Latinas, Blacks, and immigrant women do so. We know virtually nothing about the attitudes of ethnic minority and immigrant women toward amniocentesis, why their refusal rates tend to be higher than other women, whether their reasons for accepting and refusing are similar to women from other backgrounds, and what their own decisions mean to them.

Our research was designed to address these issues. Our aim was to investigate how a group of low-income Mexican-origin women and their male partners decided whether to undergo amniocentesis after the woman had screened AFP positive and to gain insight into the meaning of amniocentesis refusal for those who declined the test. We focused on the Mexican-origin population because it is large, young, and rapidly growing, with one of the country's highest birth rates (California Department of Health Services, 1995). Mexican-origin women (and other Latinas) are also at higher risk for neural tube defects than any other U.S. group (Stierman, 1995). Yet California data indicate that Latinas are more likely than women from other groups to refuse fetal testing (Cunningham, 1998). There has been little systematic research on the reasons why. This account is intended to help rectify this situation.

We first examine the factors associated with amniocentesis acceptance and refusal among a group of Mexican-origin women who were offered the procedure because they had screened AFP positive. Next, we describe the actions taken by those who refused the test subsequent to turning down the procedure, and we describe the women's—and in some cases their male partners'—explanations for their acts. We show that although study participants' ideas about what put their pregnancies at risk tended to be at odds with those of cli-

nicians, their objectives were similar: to reduce risk and to maintain hope in the face of uncertainty.

Method

These data were collected in the context of a larger project designed to understand the use of amniocentesis by a group of Mexican-origin women and their male partners living in Southern California. All the women in the project had screened AFP positive. In California, those who test positive are referred to a California state-approved prenatal diagnosis center where they are offered genetic counseling and a high resolution ultrasound exam. In about half the cases, the sonogram reveals why the woman screened positive, most often because the pregnancy was either more or less advanced than had been thought. Should the pregnancy appear to be normal on the sonogram, the woman is generally offered amniocentesis.

Amniocentesis is a procedure in which a physician inserts a 3 1/2 in. hollow needle into the uterus to remove a quantity of amniotic fluid. It is generally performed under local anesthesia. Complications from amniocentesis are uncommon but include cramping, bleeding, infection, and occasionally fetal injury or miscarriage (Eiben et al., 1997; Marthin, Liedgren, & Hammar, 1997). Miscarriage rates following amniocentesis in California hospitals can range from 1 in 500 to 1 in 200 (Authors' unpublished field notes, 1996). The vast majority of women who screen AFP positive ultimately give birth to normal, healthy children, and no definitive explanation for the positive screening test result is ever found: Of every 68 women who screen positive, 67 will bear children without detectable anomalies (J. M. Green, 1994).

We conducted semi-structured, face-to-face interviews with two waves of eligible Mexican-origin women. The interviews were administered after the women had decided whether to have amniocentesis, but some were still awaiting their results. When possible, we also interviewed their male partners. Participants were recruited from six 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 (defined as Mexican-origin women with Latino partners who had been offered amniocentesis after a positive AFP result) were included in the interview sample.

Questions explored in the pilot study were evaluated and the most reliable, comprehensible, and informative questions were incorporated into a semi-structured 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.

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. Of the participants, 69% ($n = 184$) chose to be interviewed in Spanish and 31% ($n = 83$) in English. Interviews were generally conducted in participants' homes with some follow-up interviews by telephone.

Interview results reported here are based on combining the responses from the pilot and main samples. A quantitative code book was developed after a portion of the interviews had been completed and questions amenable to either nominal or ordinal coding were coded in this manner. For nominally coded questions, we reviewed a sample of the interview responses to establish coding categories and added additional categories as needed. For example, in an open-ended format we asked, "Why do you think you tested positive on the AFP screening test?" Responses included, "I have no idea," "The test is wrong," "weakness," "stress," and others such as substance use or abuse by self or spouse. Examples of questions coded ordinally were the following: "On a scale of 1 (*the worst*) to 10 (*the best*), how would you rate the genetic counseling you received?" and a number of questions that asked for a response on a 4-point scale (*none/nada; a little/poco; quite a bit/bastante; a lot/mucho*). These included (for those who agreed to amniocentesis), "How worried were you waiting for the results of your amniocentesis?" Questions coded qualitatively were subjected to content analysis, with all responses to a single question or topic analyzed for content and patterns (Patton, 1990). Both types of coding were performed by two members of the research team who read through each interview and independently scored each question. A third member of the research team was consulted to resolve disagreements in coding.

Results

Table 1 provides basic sociodemographic characteristics of the women and male partners who were interviewed. The women reported an average of 2.01 previous pregnancies (range = 0 to 8; $SD = 1.94$). Forty-six of them (31.3%) reported miscarriages, with 73.9% ($n = 34$) reporting just one and the rest between two and four. Out of 140 women, 25 (17.9%) reported one or more induced abortions; 84.0% reported one and the others reported two or three. Of 145 women, 15 (10.3%) said they had children who died (13 reported one and 2 reported two), and 10 out of 144 women (6.9%) said they

had children born with anomalies. (Denominators are less than 147 due to missing data.) There were no statistically significant differences between these reproductive characteristics and those of the 379 Latinas who were offered amniocentesis at four genetics clinics in Southern California in 1996 (Browner & Preloran, 1999).

Ninety-one of the 147 women interviewed (61.9%) accepted the offer of amniocentesis and 56 (38.1%) declined. (All but two of the amniocenteses were negative. Both who tested positive opted for abortion. In addition, the high resolution ultrasounds of two women who refused amniocentesis indicated the likelihood of problems. One miscarried and the other gave birth to a baby with multiple anomalies.) This acceptance rate is significantly higher than the 53.4% of women in the larger and more random chart sample described above. No obvious sociodemographic factors differentiated those in our interview sample who accepted amniocentesis from those who declined.

Few sociodemographic factors differentiated the two groups of women or their partners. We found no significant differences in age, educational background for either sex, household income, religious background, or religiosity. Both groups of women had similar reproductive histories (i.e., pregnancies, miscarriages, induced abortions, children who died, children with birth defects), and there was no difference in family histories of birth defects.

We had hypothesized that participants less acculturated to the United States would be more likely to decline amniocentesis. This hypothesis received partial support. Women born in Mexico were more likely to refuse amniocentesis ($\chi^2 = 4.67$; $df = 1$; $p = .031$), but neither scores on a standardized acculturation instrument (Marín, Sabogal, Marín, Otero-Sabogal, & Perez-Stable, 1987) nor, for immigrants, length of time in the United States was predictive. For men, neither birthplace, acculturation score, nor length of time in the United States was associated with the amniocentesis decision.

It is commonly assumed that women agree to amniocentesis to choose to abort an affected pregnancy, whereas abortion is not an option for those who refuse (Cowan, 1993). Our data show that the reality can be far more complex (see Table 2).

Although the women in our study who declined amniocentesis were significantly more likely to describe themselves as strictly opposed to abortion ($\chi^2 = 11.29$; $df = 3$; $p = .01$), there was, in fact, significant overlap between the two groups of women in their abortion views. Fully 42% of women who accepted amniocentesis said they would never consider an abortion. At the

Table 1. Characteristics of the Study Population

	Women (N = 147)		Men (N = 120)	
	n	%	n	%
Ethnicity ^a				
Mexican American	45	30.6	34	28.3
Mexican immigrant	102	69.4	76	63.3
Other Latino	—	—	10	8.3
Education				
6 years or fewer	37	25.3	31	26.7
7 to 9 years	72	49.3	60	51.7
10 or more years	37	25.3	25	21.6
Household income				
Less than \$10,000/year	49	34.5	34	28.8
\$10,001 to \$20,000/year	42	29.6	43	36.4
20,001/year or more	39	27.4	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: *n* is less than 147 for women and 120 for men due to missing data.

a. For sample recruitment, *Mexican American* was defined as being born in the United States or having emigrated prior to completing primary school, *Mexican immigrant* as having emigrated after completing primary school, and *other Latino* as non-Mexican Latino who emigrated after completing primary school.

Table 2. Abortion Attitudes of Women Who Accepted and Declined Amniocentesis

	Women Who Accepted (N = 89)		Women Who Declined (N = 58)	
	n	%	n	%
Would never consider an abortion	37	41.6	39	67.2
Only in extreme circumstances	33	37.1	14	24.1
Would consider an abortion	14	15.7	2	3.4
Don't know	4	4.5	2	3.4
Total	88	98.9	57	98.1

NOTE: *n* does not equal 89 for women who accepted and 58 for women who declined due to missing data.

same time, more than one fourth of those who declined said they would consider an abortion under certain circumstances, and an additional 4% of refusers said they were not sure. We found no association between men's views on abortion and amniocentesis decisions.

What, then, led some of the study participants who had been told there might be a problem with their pregnancies to agree to further diagnostic testing and others to decline? We found their reasons many and varied. Participants in the pilot phase of the research gave 30 different reasons for their decision to either accept or decline amniocentesis. We subsequently asked the participants in the main study to rate on a 4-point scale (*nada/not at all, poco/a little bit, bastante/quite a bit, mucho/greatly*) the extent to which each of the 30 considerations contributed to their own decision. We found that spouses tended to report similar reasons for their decisions, regardless of whether the interview was individual or joint.

The strongest differences between those who declined and those who accepted amniocentesis were found in their attitudes toward doctors, medicine, and science. Those who agreed were more likely to indicate that physician recommendations were an important factor in their decision ($t = -9.04$; $df = 143$; $p < .001$). They were also significantly more likely to believe that the positive AFP result meant something could be wrong with the pregnancy ($t = -13.92$; $df = 122$; $p = .000$), that a positive amniocentesis would provide doctors with information that would help their fetus or baby ($t = 5.29$; $df = 133$; $p < .001$), and that a negative amniocentesis would resolve uncertainty and provide reassurance ($t = -12.51$; $df = 98$; $p < .001$). In contrast, those who refused were more skeptical about the accuracy and value of scientific information ($t = 4.89$; $df = 84$; $p < .001$), and they reported a higher degree of discomfort with technology, machines, and needles ($t = 3.64$; $df = 115$; $p < .001$). Those who refused were also much more likely to believe that the fetus was healthy, despite the positive screening-test result ($t = 4.57$; $df = 107$; $p < .001$) (Browner, Preloran, & Cox, 1999).

Attribution and the Meaning of Hope

We found other provocative differences between those who accepted and those who declined amniocentesis with regard to the meanings they attributed to the positive screening-test result. These explanations were closely linked with actions that were subsequently taken. Most who agreed to amniocentesis found the answer to the question, "Why do you think you screened AFP positive?" self-evident. They simply reiterated a variant of the medical

explanation that clinicians had offered them (e.g., “We just don’t know,” “It’s just something that happens,” “It could happen to anyone,” etc.).

Responses to the same question by those who declined amniocentesis were much more nuanced and complex. This is perhaps not surprising, given that those who deviate from the norm tend to feel a greater need to account for their behavior (Press & Browner, 1997). Although most who refused the amniocentesis did not reject out of hand the biomedical explanation for their positive screening test, they found it too abstract, general, or generic to provide a satisfactory reason for why they themselves had screened positive. Instead, they sought to connect the positive test result in a direct and specific way to their own personal history or past experience (cf. Hunt, Browner, & Jordan, 1990; Hunt, Valenzuela, & Pugh, 1998). This line of thinking had two effects. Those who refused amniocentesis tried to generate plausible alternative explanations for having screened positive, and they embarked on a course of practical action in an effort to try to alleviate the problem (Lewis, 1995). The lack of effective biomedical solutions provided no barrier. Study participants turned instead to techniques derived from traditional or alternative medicine in their efforts to restore their pregnancy to a healthy state of being and, in the face of uncertainty, keep hope alive for a favorable outcome.

Before providing a detailed description of these alternative explanations and the actions women took in response to them, we offer one woman’s case to provide context and depth for the briefer narratives that follow. We selected Soledad’s case (all given names are pseudonyms) because she is typical of the larger study population both demographically and in her reactions to the positive screening-test result, the explanations she drew on to give meaning to the positive screening-test result, and the actions she engaged in even while turning down amniocentesis.

Soledad, who was 24 at the time of our interview, was born in Tijuana and first came to the United States when she was 12, spending a year and a half attending school in the San Diego area before returning home. She did not return to California until she was 20, when she married a Mexican man who had been living in the United States. Their first years of marriage were difficult financially, with both of them out of work, but eventually he found a job in a cardboard box factory and she as a teacher’s assistant. In 1993 she became pregnant for the first time but miscarried 3 months later, attributing the miscarriage to stress and economic uncertainty. It took 2 more years for Soledad to again become pregnant. She was very relieved and a bit nervous, for she dearly longed for a child.

When we asked Soledad about her reactions on learning she had screened AFP positive, she replied that it was hard for her to accept the possibility that anything could really be wrong. She explained,

I decided to go [to the follow-up prenatal diagnosis center] because I was sure they were going to find out that my dates were all wrong . . . [The dates of] my periods . . . are absolutely crazy. . . . So when I came [to the genetics consultation] I was okay—maybe just a little scared. . . . But when [the counselor] came with the [normal] ultrasound result, I knew something had to be wrong. [She told me] “We need to check more. Have you thought of the other test [amniocentesis]?” I told her that they should keep looking for the dates. But she didn’t want to repeat the ultrasound . . . and I thought to myself, “I’m okay, I eat well; I take my vitamins.” I couldn’t believe there was something wrong.

When [the counselor] again said, “The only way to know about your baby’s health is with amniocentesis,” I said, “I have to think it over.” I told her that I knew that my age was out of the question: I’m just 24. [And] we don’t have [any health] problems in our families. . . . I’m taking good care of myself; I don’t drink; I never smoked. . . . My only explanation was . . . my period. I thought, “Could anything have happened?” We didn’t hurt anybody, [it’s not that we could be] punished in this way. At first I thought I should look for a second opinion, maybe in another hospital. But I have my insurance here. . . . I was convinced it was simply my period. . . . My husband was more certain than I [about refusing]; he believed that the blood test could be wrong. His grandmother was also against the test [amniocentesis]. She told me to be careful around my husband’s cousin because she envies us. But my husband said I shouldn’t fill my mind with old wives’ tales.

All I wanted was to go home . . . but my husband was at work. So I went to work and I talked to my boss. And she told me, “These issues of [genetics] science are still in their infancy. . . . This is why [doctors] can’t cure those problems. . . . Besides, you plan to have the baby, regardless of how it comes out, don’t you?” I said, “Yes. . . .” And she said, “You know you can always count on us. If the baby comes with problems we can help take care of him. He would never be better loved and cared for anywhere else.” That was a great relief: knowing I could count on her. She insisted I should rest, take a vacation, relax . . . and since she’s my boss, I said, “Fine.” And then she said that with all that moving [Soledad had recently moved to the area], I could have lowered my defenses. So I might have had the test [AFP] on a bad day and that was all.

Like other women in our study who refused amniocentesis, Soledad simultaneously drew from biomedical and lay understandings in an effort to understand why she had screened positive (cf. Marín & Marín, 1991). Soledad was, in fact, actively pursuing prenatal care and was not at all resistant to “high-tech” medicine such as ultrasound, nor was she particularly worried by the positive screening-test result. She even welcomed the genetic

referral in the expectation that it would confirm her belief that the screening test was in error. She did not become discouraged when the ultrasound proved inconclusive and remained unconvinced that so drastic a step as amniocentesis was really necessary. Instead, Soledad searched for alternative explanations for the inconclusive sonogram. She considered and then discarded all of the possible reasons she knew could have caused her to screen positive. This process reinforced Soledad's belief that her pregnancy was not in danger. At the same time, she approached people she trusted to gain more information and, with their support, established a course of action.

Soledad's explanations for why she had screened positive and the actions she took in response were not unique. Other study participants also gave credence to the possibility that their pregnancies might be at risk, but in contrast with those who agreed to amniocentesis, this possibility was seldom simply taken at face value. Instead, it was critically evaluated with family and friends or individually reviewed in light of previous knowledge and experience. These discussions and analyses generated a variety of alternative explanations about the possible causes for the positive screening-test result, explanations that generally were outside the biomedical paradigm or drew on it in unconventional ways.

Below, then, is a description of the explanations for testing AFP positive given by those who refused amniocentesis and an account of the actions the women took in response (see Figures 1 and 2). However, a methodological caveat is in order. All study participants were asked, "Why do you think you [your partner] screened [AFP] positive?" Put so directly, the question generally elicited shrugs and blank stares. However, the topic came up frequently in casual conversation before, during, and after the formal interviews. The material reported here is drawn from these broad-ranging informal conversations.

The most common explanations for having screened positive were derived from circumstances associated with the pregnancy itself or the concrete material conditions within which the women lived. Weakness (*debilidad*) was the most common explanation. Participants offered diverse factors which could have caused or contributed to weakness, including poor diet, malnutrition, vomiting, and having lost excessive blood during testing or for other reasons. Some merged biomedical and lay understandings to explain how they had become weakened.

Berta, demographically representative of our population, was 24 years old and living with her husband in a modest apartment in East Los Angeles that they share with another couple. When we interviewed her, she was pregnant for the second time, had no previous miscarriages or abortions, and considered herself in excellent health. She confessed to having always been a picky

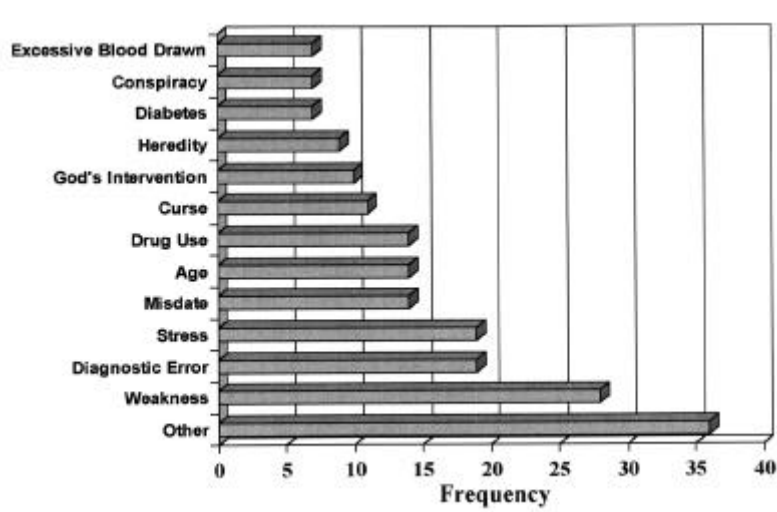


Figure 1. Explanations for screening AFP positive by Latinas declining clinicians' offer of amniocentesis.

NOTE: AFP = alpha feto-protein. $N = 58$. Multiple responses allowed.

eater and even more so now that she was pregnant. Berta's understanding was that AFP measures the amount of protein in the blood of a pregnant woman. Told she had screened low, she reasoned that a dietary deficiency caused her own low reading and she resolved to drink more milk, although she hated its flavor.

Others believed that the AFP, which is popularly referred to as "the blood test" (*la prueba de la sangre*), is like a CBC (complete blood count), which is routinely administered during pregnancy to detect anemia (which is sometimes similarly linked to protein deficiency), among other things. Some, like Carla, who assumed that her low AFP score was an indication of anemia, promptly changed their diets to incorporate more protein-rich foods including yogurt, cheese, and beans. Others added calcium, vitamins, or iron, tried to rest more often, or tried to get more help from family members with household chores and other responsibilities. For example, although Rosalia continued to experience intense vomiting well into the second trimester of her pregnancy, she went to great lengths to determine what foods she could tolerate (green beans and sour cream) and added them to her diet although she disliked both of them.

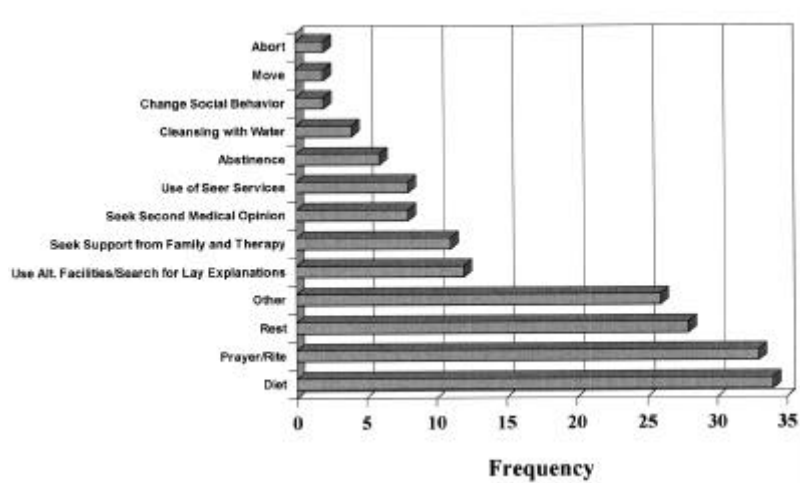


Figure 2. Actions reported by Latinas declining amniocentesis following positive alpha fetoprotein screening.

NOTE: $N = 58$. Multiple responses were allowed.

The pressures of daily life, glossed as “stress” (*estrés*), were another very common explanation. Stress was attributed to job conditions, emotional problems, and economic setbacks and manifested in anxiety and depression, which participants feared would have negative effects on the pregnancy. Susana explained, “I got my AFP positive because I was under a lot of pressure, my husband couldn’t find a job. . . . I was afraid that we might have to move or go back [to Mexico] if we couldn’t pay the rent.” But Susana, like several other women, was able to use the bad news of screening positive to make positive life changes. In a follow-up phone conversation several weeks after the face-to-face interview, we learned that Susana had moved in with her sister for the duration of her pregnancy where she would have less housework and more time for relaxation. She was also no longer fearful she would be forced to return home to Mexico because there wasn’t enough money to pay the rent.

Other stresses were brought on by terrifying experiences (*sustos*), many of which were associated with life in an unfamiliar or otherwise dangerous metropolitan area. Rosa, for instance, who had been mugged on the street,

explained, "I believe [the AFP positive] could have been due to the *susto*. I went through a lot the day before the test. . . . This man pushed me and I fell. . . . I was really, really frightened." At the time we met, Rosa was undergoing massage therapy (*sobada*), which she hoped would cure her injuries and reduce the stress caused by the mugging. She was, however, disappointed with the results. Several days after our interview, she phoned us for a psychological referral, explaining, "With that [AFP] test and all the things going on in my life, I can't afford to sit on my hands; I have to do something to avoid problems for my baby." Others who attributed their positive test result to stress similarly sought help from psychologists, psychics, and massage therapists. Some ended conflictive relationships or went to church more often.

Life circumstances of a different sort figured in causal explanations when the reason given for testing positive was the use of prescription or illicit drugs by women or their partners. Alejandra, for example, reported that her mother believed her daughter had screened positive because of an injection she had been given by a Mexican physician she consulted in an effort to regulate her menstrual cycle. When women believed that the positive test result was due to their own use of substances, they responded by stopping their use, drinking large quantities of water "to clean the system," and by intensifying prayer. If their partner's drug use was the issue, they tried to convince him to drink water to purify his body and cease his use of substances.

Others attributed the positive test result to error due to the technology's limitations. Many believed that the test was simply wrong. They supported their belief with their knowledge that women often do screen positive but give birth to healthy babies. Moreover, providers often sought to reassure anxious women who had screened positive and their families by saying that in any event everything was likely to prove normal despite the positive screen. Study participants took this to mean that the test often gave inaccurate results.

In this regard, the case of Pedro and Marta was typical. Pedro was 23 at the time of the interview and had been in the United States just 7 months, but he had quickly found steady work in building construction. He said that both he and his wife, Marta, enjoyed good health. Since their recent marriage, they had been living with Marta's parents, and Marta's mother, Amalia, accompanied them to the genetic consultation. The two women met with the genetic counselor while Pedro waited outside the office watching a child his wife and mother-in-law were babysitting, helping them "protect their job," he explained.

He was pleased when he learned that Marta had refused the amniocentesis, although he said she made the decision before consulting him. He explained,

I'm 100% behind her. She is very responsible; she knows what she is doing. It's our first child, but her mother was there, and she has five children. When they called her and told to go [for counseling] she told me, "They would like to do some testing; they take water from the womb. . . . I don't want to do it, what do you think?" "It's your body . . ." I said. "Don't do it if you don't want to. . . ." [Later] she explained everything to me. . . . The problem was that a test that showed she was weak because she had no proteins, or little proteins, I don't remember, and the test was wrong. That's what my mother-in-law told me. The doctor in the hospital had said to her, "Why haven't you taken your vitamins before getting pregnant? Didn't your doctor tell you to do that?" And my wife said that she didn't know. Do you understand they said "before" getting pregnant! It is to avoid problems with the bones. But how can one know when one is going to get pregnant? We just got married, we didn't know it would happen so soon. My mother-in-law said not to worry, because when Marta was waiting for the ultrasound she talked with a nurse and the nurse said not to be worried. [The nurse said] she simply needs to start those vitamins right away and the protein will pump up. Besides, in the other Hospital they told her that most of the time the [AFP] test comes out wrong."¹

Those who suspected that the AFP test was inaccurate and went on to have a negative amniocentesis were given technological reassurance that no detectable birth defects had been found. In contrast, those who turned it down had no equivalent reassurance within the biomedical paradigm. These women sought alternative ways to alleviate fears that the positive screening test might have produced. Notable among these were the intensification of prayer and the use of other religious strategies, such as traveling to Mexico to see a renowned healer or paying for a mass to be celebrated "for the good of the baby." These actions in the spiritual realm were generally accompanied by long talks with friends and family, which alleviated anxiety and provided information.

Age was one explanation where overlap between lay and biomedical understandings was seen, although participants did not necessarily regard age to be a risk factor in the same way as clinicians. A few, for instance, thought that the positive test could be due to the age of the father of the baby. Many, however, did believe that a woman's age could affect her pregnancy outcome. However, the statistical relationship between age and risk that women were told about during the genetic consultation was generally forgotten, downplayed, or dismissed. Maria's views were typical:

I believe that it's better to have children when you're young . . . But I'm not afraid, I'm only 33 . . . and I feel fine. . . . My mother had her last child when she was over 40 and my brother is perfectly normal. . . . My husband said that the

test [AFP] came out bad because I'm a little older . . . [and] that I should rest more. . . . And since I've been sleeping more now, I feel much better.

Other women who attributed the positive test result to age similarly reduced physical activities (e.g., by sleeping later, having someone else bring their children to or from school) and intensified prayer.

Heredity and family background were other biomedical explanations occasionally mentioned. In contrast with biomedicine, however, participants did not view such conditions as unalterable. Manuel, for example, explained,

My brother's son was born with the same thing the counselor mentioned to us [spina bifida], and over there, in Mexico, doctors told my brother that this child would be a retarded invalid. Thank God, he grew up fine. . . . The little hole he had in the spine, little by little . . . it closed itself when he was 3 years old, without any doctor or medicine. I don't know if it was because of our prayers, or thanks to [the work] of nature, but he is fine. We're going to do the same, praying until we dry out our mouths and hope for the best.

As with age, when heredity, another seemingly unalterable condition, was thought to be the cause of the positive screen, intensifying prayer and reducing physical activity were the actions most often taken.

Others, like Soledad, sought to adopt the biomedical explanation that they had screened positive because their pregnancy was either more or less advanced than had been thought. For some, this proved a vindication of the woman's own embodied experience. Fernanda, for example, said,

I feel perfectly fine; I feel the baby move. They say that the test came out bad because the dates were wrong, and how could one be 100% sure of the date, anyway? I believe the test came out bad because they did it to me too early. The same thing happened to my neighbor.

Supernatural explanations were mentioned on occasion, although such explanations may in fact have been more common than reported because many sought to downplay the extent of their own beliefs in such superstitions. The two most common were fear of having been cursed and fear of Divine retribution. Some women feared that their partner's current or former lover was responsible (Browner & Preloran, 1999) or, like Soledad, that the curse could have been brought on by envy (*envidia*). Graciela, for instance, said that her positive AFP was probably caused by a neighbor who was herself unable to have children. Study participants who believed they had been cursed responded by seeking the services of a specialist who could break the spell, by moving to where the spell would be less powerful, and, in a single case, by terminating the pregnancy. The fear of Divine retribution for wrongdoing was also occasionally mentioned. One such case was Cristina, who

said, "I'm convinced I tested positive because I was so impatient with my husband. I argued with whatever he said. But after the positive test, I changed. I've become much more patient and understanding." Others made similar changes, attempting to correct behaviors they viewed as sinful and by intensifying church attendance.

A wide range of additional explanations that for the most part, derived from women's objective life conditions provided an impetus for life changes or other types of action. For example, study participants who attributed their positive screening test to diabetes stopped eating sweets or in other ways altered their diets. Some who feared that excessive blood loss was the cause tried to restore the lost blood through protein-rich foods and more rest. Some held conspiracy theories, blaming either economic or eugenic motives. A few of these participants were skeptical about the value of prenatal testing, speculating that amniocentesis was offered only for profit. When these beliefs prevailed, women switched their prenatal care to small, low-cost neighborhood clinics perceived to be more friendly, less profit driven, and where no amniocenteses were offered. Others believed that fetal diagnosis and abortion were part of a genocidal effort to control high Latino birth rates. In the two cases where this type of conspiracy theory was reported, in both instances by male partners, no action was taken on the women's part.

Fetal misplacement and blows to the body were mentioned occasionally and treated with bed rest and massage therapy. Environmental explanations such as living too close to high-voltage power lines, also figured occasionally in the causal explanations and were resolved by moving elsewhere to live. The possibility that the positive test result was a random event, which genetic counselors tell women is the most common reason for screening positive, was mentioned only twice by amniocentesis refusers.

Discussion

These data offer insight into the reactions of a group of Mexican-origin women and their male partners to a screening test result which indicated that their pregnancy could be in danger and the reasons they gave for either accepting or declining an invasive and inherently risky diagnostic procedure. The association other researchers find in Euro-American women between socioeconomic variables and amniocentesis decisions was not the case in our Mexican-origin population, although this may reflect the homogeneity of our sample. Unlike other research, none of our variables concerning religious background or religiosity predicted amniocentesis uptake in our study population.

Like other studies, we did find an association between negative abortion attitudes and amniocentesis refusal. However, the pattern was complex in that a significant proportion of those who agreed to amniocentesis described themselves as adamantly opposed to abortion, whereas a large proportion of those who declined would themselves consider an abortion under certain circumstances. Our data are also consistent with other research that finds positive associations between amniocentesis refusal and the fear that the fetus could be harmed by the procedure, the belief that the fetus is in good health, and the view that the amniocentesis is what the doctor wants. On none of these dimensions, then, are the Latinas in our study different from women from Euro-American backgrounds.

Where they do appear to differ, however, is in their explanations for the positive screening-test result and the actions they took on learning of it. We know of no other research that has investigated this issue, so we cannot compare these findings with the explanations and actions of women from other ethnic groups.

Virtually all of the study participants who refused amniocentesis did something in response to their positive AFP result. Although behavioral changes were very common, religious actions were also prominent. In fact, religion appeared to motivate action. Faith moved patients to perform rites and attend church more often, and caused women to modify their work schedules so that they could attend prayer group meetings. Faith led them to search for loans to pay for spiritual services. Faith, as in the axiom that "God helps those who help themselves," was reinforced when social support was received after reaching out into the religious communities. Women found that fellow parishioners offered them not only prayers but also housing to ensure a more restful environment.

In seeking to make sense of the positive screening-test result, study participants often blended biomedical and lay information. Some attributed the positive screen to things they learned in the genetic consultation, but their interpretations often differed from medical ones. Others initially agreed with biomedical explanations, but subsequently found that additional information or circumstances led them to change their minds. Still others went to the genetic consultation with lay explanations but left having incorporated new ideas.

Faced with the complexity and ambiguity of genetic information, women and their partners who refused amniocentesis looked beyond the medical world for options. Yet, in analyzing their actions, we found that these alternative explanations and actions did not come without cost: In refusing, they lost the chance for reassurance through technology. At the same time, however, these individuals drew on a different kind of hope to manage the uncertainty

that the positive screen had produced. This “reasonable” hope allowed them to maintain their motivation to work actively in an effort to reverse their adverse pregnancy conditions. Mario, whose wife Lidia felt she might have screened positive because a disgruntled neighbor had hired a *curandera* (seer) to cast a spell on Lidia, discouraged his wife from attending a spiritual cleansing. He was articulate in his explanation: “There is a wishful hope, as the one I have to win the Lotto . . . and a reasonable hope, as the one I have of seeing my children healthy and getting an education if [my wife and I] work hard.” He added,

I believe her blood test was low because she was very tired working outside the home and with the children. . . . I think when she had the [AFP] test, she was weak. I told her she must eat more and sleep more, and I’d help her with the [household] chores. I don’t believe she got it because of evil spirits.”

Reasonable hope gave many like Mario and his wife the strength to cope with uncertainty.

We were surprised by the diversity of explanations participants who refused amniocentesis gave for the positive screening-test result. But in contrast with those who agreed to the procedure, most who refused gave explanations that could be ameliorated by human action. Even causes considered unalterable by human means were actively responded to by searching for supernatural assistance. Yet, reasonable hope was not the sole purview of those who refused amniocentesis. Those who agreed similarly managed their uncertainty with the hope that the test results would provide reassurance. They engaged actively in deciding whether to be tested and in preparing for the procedure. And through increased prayer and other spiritual strategies, they, too, were active throughout the difficult period of waiting for the test results.

As with many other types of medical care, prenatal genetics services, including amniocentesis are turned down more often by low-income Latinos than most other U.S. groups. Health providers often attribute this to fatalism: the view that one’s destiny is predetermined and unalterable. Our intent has been to show that at least in the case of amniocentesis, Latinas’ greater propensity to decline the procedure may have nothing to do with fatalism. The causal explanations given by these Mexican-origin women and their partners for the positive AFP result and the actions the women took on learning the result for the most part fell outside the biomedical paradigm. Their actions indicated they regarded the fetus to be in a fluid state of formation; the problem, therefore, could be transient or remediable. This contrasts with the biomedical view that assumes that the fetus is a stable entity and that problems

detected prenatally are unalterable. These ideas and behaviors demonstrate that an action-oriented approach to life is not exclusive to Euro-Americans and offer a powerful challenge to a persistent negative stereotype about Latino health behavior.

What, then, are the implications of these findings for the delivery of prenatal genetics services, and particularly for facilitating cross-cultural communication between genetics counselors who are trained in the biomedical paradigm and, for the most part, are not Latino and clients from Latino backgrounds? Genetic service providers should be trained and encouraged to create a nonjudgmental environment in which their clients feel they can express their fears about the pregnancy and their own views about why the woman screened positive. Throughout a genetics consultation, counselors should encourage clients to repeat what they understand the counselor has told them about the nature of their pregnancy risk. This should include options regarding fetal diagnosis and treatments if an anomaly is detected, as well as the ambiguities and limitations of human genetic information. Because most conditions that can be detected by amniocentesis have prognoses that are variable or uncertain, turning down genetic information or services reflects Latinas' efforts to keep hope alive in the face of uncertainty. Clearly their acts do not represent a rejection of biomedicine, nor should they be construed as evidence of fatalism in health-care behavior.

Note

1. HMP was present with Marta and her mother throughout the entire ultrasound exam and did not observe the above interaction Pedro described between his mother-in-law and a nurse.

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