
Characteristics of Women Who Refuse an Offer of Prenatal Diagnosis: Data From the California Maternal Serum Alpha Fetoprotein Blood Test Experience

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This paper presents data from the California maternal serum alpha fetoprotein (MSAFP) program in order to explore the effect and interaction of various factors, especially ethnicity, abortion history and attitudes, religion, and religiosity on MSAFP test decision. The intent is to describe which women are more likely to reject MSAFP screening and also to understand the reasons for refusal and the meanings associated with it. We obtained data on sociodemographics and reproductive history from 595 obstetrical patient charts; we conducted semistructured interviews with an additional 158 pregnant women who were European-American, English-speaking Latina, or Spanish-speaking Latina. All of the women had been offered screening within the context of California's MSAFP Program. We found that women who had never terminated a pregnancy, Spanish-speaking Latinas, and women who scored high on a religiosity scale were significantly more likely to refuse testing. However, we found that all of those factors were strongly mediated by the effects of ethnicity and acculturation, producing different patterns of association in different groups of women. *Am. J. Med. Genet.* 78:433–445, 1998 © 1998 Wiley-Liss, Inc.

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INTRODUCTION

Little more than a decade ago prenatal diagnosis was the province of women over 35 and others considered to be at high risk for bearing a child with a chromosomal abnormality. However, since the advent of the maternal serum alpha fetoprotein (MSAFP) blood test, an offer of prenatal screening has become part of routine care for an increasing number of young and low-risk pregnant women. In the mid-1970s, it was found that elevated levels of alpha fetoprotein in maternal blood were associated with increased risk of fetal neural tube defects, anomalies of the brain and spine that are among the most commonly reported serious birth defects [Brock and Sutcliffe, 1972; Brock et al., 1973]. This finding led to development of the relatively inexpensive MSAFP blood test, which posed no physical maternal or fetal risk and could be used to screen all women for the possible presence of fetal NTDs. When maternal AFP turned out also to be a marker of risk for Down syndrome [Merkatz et al., 1984; Cuckle et al., 1984], interest in the screening increased. In many medical settings worldwide, most women accept MSAFP testing, although screening rates range from close to 100% to only about 30% [UK Collaborative Study, 1977; Brock et al., 1978; Wald et al., 1979; Macri et al., 1979; Bennet et al., 1980; Gardner et al., 1981; Roberts et al., 1983; Berne-Frommel et al., 1984; Doran et al., 1987; Kyle et al., 1988; Byrne-Essif et al., 1988; Sanden and Bjurulf, 1988; Marteau et al., 1989; Deukmejian et al., 1990; Sikkink, 1990; Madlon-Kay et al., 1992].

Only a handful of studies worldwide have addressed the question of which women are most likely to refuse MSAFP screening [Bennet et al., 1980; Berne-Frommel et al., 1984; Sikkink, 1990; Dembert et al., 1983; Faden et al., 1987; Jorgensen, 1995b; Tymstra et al., 1991]. Contradictory findings have been reported on the relationship between test decision and socioeconomic status [Berne-Frommel et al., 1984; Sikkink, 1990; Jorgensen, 1995b; Tymstra et al., 1991], age [Berne-Frommel et al., 1984; Sikkink, 1990], marital status [Berne-Frommel et al., 1984; Sikkink, 1990], and inter-

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est in discussing the test decision with others [Dembert et al., 1983; Tymstra et al., 1991]. Ethnicity was not found to be a significant predictor of test decision [Berne-Frommel et al., 1984], although the potentially interacting effects of acculturation, socioeconomic status, or religiosity on ethnicity and test decision have remained virtually unexplored.

Objection to abortion, usually for religious reasons, is generally assumed to be the main reason why women refuse MSAFP testing. The reasoning behind this assumption is based on the fact that prenatal diagnosis can currently detect, but not cure or treat, disabling conditions. Therefore, the only way to avoid the birth of a child with birth defects is by terminating the pregnancy. Certain religions, especially Catholicism and Fundamentalist Protestantism, teach that life begins at conception and oppose abortion as murder. Use of prenatal diagnosis is seen in these religious traditions as encouraging abortion. Therefore, it is not surprising that women who refuse MSAFP have been found to be significantly more likely to express moral, religious, or ethical objections to testing [Bennet et al., 1980]; to participate more in Church activities [Berne-Frommel et al., 1984; Tymstra et al., 1991]; and to have a more negative attitude toward abortion in general or the abortion of an affected fetus in particular [Berne-Frommel et al., 1984; Jorgensen, 1995a]. Yet the only study that looked at a woman's own abortion history found no such relationship [Berne-Frommel et al., 1984].

The purpose of this paper is to examine this question of which women refused MSAFP testing. Specifically, we report data from the California MSAFP program in order to explore the effect and the interaction of various factors, especially ethnicity, abortion history and attitudes, religion, and religiosity on MSAFP test decision. Our intent is not only to describe which women are more likely to reject MSAFP screening but to understand better the reasons for refusal and the meanings that may be associated with it. Our use of a combination of quantitative data, which has the statistical power to reliably identify the factors leading to test refusal, with qualitative data, through which the meanings of women's decisions can be explored, should enable us to begin to achieve this goal.

MATERIALS AND METHODS

In 1986, California became the only state to mandate that all health care providers offer MSAFP testing to every pregnant patient who begins prenatal care prior to the 20th week of pregnancy. It is in the context of this state program that we undertook research into pregnant women's use of, attitudes toward, and understandings about MSAFP. Between 1989 and 1992 we conducted participant observation, interviewed health care staff, collected information from patient charts, and recruited subjects for interviews from five sites of a large health maintenance organization (HMO) in Southern California. The HMO had contracts with private employers and with MediCal (California's Medicaid program). All five sites had both MediCal and employer-insured patients. At all sites the majority of pa-

tients were European-American or Latina (both U.S.-born and recently immigrated).

Although during the period of data collection all sites experimented with different protocols in an effort to find the most efficient way to provide prenatal services, the similarities among sites were much greater than the differences. Most importantly, MSAFP was always discussed and offered during the first prenatal appointment, and it was always offered by nursing staff, never by a physician. As we have discussed elsewhere, company policy on MSAFP was centralized (Press and Browner, 1993), and we observed no differences in services either between sites or in response to differences in the ethnicity or educational levels of the pregnant patients. Although none of the sites employed translators, a sizable proportion of nursing staff in each site were native Spanish speakers. These nurses did all the interviews we observed with Spanish-speaking Latinas.

Two samples were obtained: a *medical chart sample* (MCS) and a *qualitative sample* (QS). These are described below. In the following discussion, we draw on both samples to explain our results, because each has different advantages. The MCS is larger and, therefore, more statistically reliable. However, as it was drawn from patient charts, it is limited by the small number of variables these charts contain. The QS, drawn from in-depth interviews, although smaller, contains information on topics unavailable in patient charts. It can therefore provide context and explanation for hypotheses generated from the MCS. It also provides an opportunity to examine additional areas of potential relevance to our research questions.

MCS

Description. We collected information from a systematic sampling of the active medical charts of patients at several sites of the HMO. The specific HMO sites were chosen because they provided only obstetric and gynecological services. All obstetric patients whose charts were kept in the file room at each site had been pregnant within the previous 2 years. Patient charts were arranged in the file rooms according to a sequential numbering scheme that was not tied to any relevant patient characteristic. Starting at a different location in each file room, we selected every 10th chart. If the woman was not an obstetric patient, or was over 35 and therefore not offered MSAFP screening, we continued on to the very next chart. (Women who are over 35 are routinely offered amniocentesis. For women who accept the offer of amniocentesis, MSAFP is often omitted as a routine office screening.) Approximately equal numbers of charts were selected from each site.

The ethnicity of the patient in the MCS was determined by two categories listed on the chart's intake form: "race/ethnicity" and "language preference." We categorized those women whose charts listed them as "Hispanic" and with a preference for speaking Spanish as "Spanish-speaking Latinas;" those listed as Hispanic with an English-language preference were categorized as "English-speaking Latinas."

Methods. We collected the following data from

each medical chart: ethnicity, age, reproductive history including number and outcome of all previous pregnancies, last MSAFP test decision, and outcome of that test.

QS

Description. We conducted face-to-face interviews with pregnant women who were patients at the same HMO sites from which we collected the MCS. Subjects were recruited into the QS with the help of HMO staff who asked all patients making their first prenatal medical appointment before the 20th week of pregnancy whether they were willing to have an investigator contact them with more details about the study. (Women who begin prenatal care after the 20th week are not offered MSAFP screening.) Approximately 10% of women either refused to have an investigator call them or refused participation in the study when called.

In order to control the size and enhance the generalizability of the QS, we limited participation to the largest Southern California ethnic groups, Latinas and European-Americans. Women were eligible for participation if they had been born in the U.S. or Mexico or could trace their ancestry to Europe or Mexico. Women who had been born in the U.S. of Mexican ancestry or had moved here from Mexico before the age of 10 were considered equivalent to the English-speaking Latinas of the MCS; in fact, all chose to be interviewed in English. Women who had been born in Mexico and moved here after the age of 10 were considered Spanish-speaking Latinas; all preferred to be interviewed in Spanish. Thus we consider the categories of Spanish-speaking and English Latinas comparable in the MCS and QS. (All of the women categorized as Latina in the QS were of Mexican background. We did not have access to data on country of origin for the MCS. However, given that 80% of Latinos in the greater Los Angeles area are of Mexican ancestry, we assume that the great majority of Latinas in the MCS were also originally from Mexico [U.S. Census, 1990].)

Only women 20 to 35 years of age were recruited into the QS, due to our interest in studying women undergoing what are medically considered "low-risk" pregnancies. Health care providers generally consider teenage pregnancies and pregnancies of women over 35 as high risk and requiring special monitoring.

Only women raised either Catholic or non-Catholic Christian were recruited into the QS. By recruiting both Catholic and non-Catholic Christians, we hoped to isolate the effect of Catholic Church doctrine on reproductive issues from religiosity and church participation more generally.

The definition and measurement of social class is the subject of considerable debate in the social sciences. Measures of educational level and income are two common categories used to measure social class. We used mode of payment for health care as a heuristic for social class, because it enabled us to categorize women before they were interviewed or recruited. Women were categorized as "middle class" if they received services at the HMO through an employer contract and "lower class" if they received services through a MediCal con-

tract. Further information on level of education and family income was collected during the interview. From this information, we constructed a "social class" variable, combining income and level of education. Women were categorized as middle or lower class based on their responses to these items. We used this new variable in the analyses reported here.

Methods. Data were collected using a semistructured interview lasting 1 to 3 hours. The interview took place after the 24th week of pregnancy, by which time the participant had received the results of her MSAFP test and any follow-up diagnostic procedures. All interviews were conducted in person by one of the two investigators or by an investigator-trained interviewer. All interviews were tape recorded and transcribed. They were then coded and entered into a computer using CRISP [Bostrom and Stegner, 1984] for data that were quantifiable and The Ethnograph [Seidel, 1988] for qualitative data.

The interview included sections covering sociodemographic information, prenatal self-care practices, reproductive history, attitudes toward childbearing and motherhood, experience with and attitudes toward disability, personal history and attitudes in regard to abortion, and attitudes and decision-making about MSAFP screening.

Included in the interview guide were 22 information questions about MSAFP. These were derived from the eight-page educational booklet provided to all sites by the California MSAFP Program, and included such items as *Have you heard the term "spina bifida"? Can you tell me what spina bifida is? Can you tell me what kinds of problems babies born with spina bifida can have? Do you know of any prenatal test that can detect spina bifida?* An AFP Knowledge Score was calculated for each subject based on their answers to these questions.

All Latinas were administered the Marin Short Acculturation Scale [Marin et al., 1987]. This 12-question, five-point Likert scale uses items such as language use and the ethnicity of friendship networks to assess the degree to which respondents have been assimilated into mainstream U.S. culture.

All women were asked to complete an investigator-designed Catholic or Protestant Religiosity Scale, depending on their self-identified religious affiliation. The Catholic religiosity scale consists of four sub-scales, each containing a varying number of multiple-choice questions. The sub-scales measured *religious background*, *religious practice*, *religious belief*, and *reproductive morality*. The latter sub-scale includes questions assessing agreement with Catholic Church teachings on premarital sex, birth control, and abortion, as well as how likely a woman was to look to her pastoral counselors for guidance in these and other matters of sexual morality.

The Protestant Scale contains three sub-scales: The questions on Religious Background and Reproductive Morality are essentially the same as those on the Catholic scale, changed only as needed to reflect differences in religious practice. Thus, for example, questions about catechism, Lenten observance, and papal infallibility were dropped from the Protestant Scale.

However, the sub-scales on religious practice and religious belief were combined into one sub-scale the questions of which comprise a 10-item reliability and validity-tested scale developed by Hoge to examine intrinsic and extrinsic factors in religious motivation (Hoge, 1973).

The investigators designed these scales because they could find no religiosity scale specific to Catholics and could find no religiosity scale at all that included questions on reproductive morality. The validity of the Catholic scale was established by comparing it to other Christian religiosity scales and by having Catholic seminary-trained laity comment on the appropriateness of the questions. The scale was reliability tested through a rotated factor analysis that produced factors completely congruent with the original construction of the scale. One question was eliminated, as it did not load on any of the factors. The Protestant religiosity instrument was also reliability tested through a rotated factor analysis that produced factors congruent with the original construction of the scale. Because Catholic and Protestant scales both loaded so well into the sub-scales, separate sub-scale scores were kept for each subject, rather than a single summed score. (Catholic and Protestant Religiosity Scales are included as Appendices A and B).

Subjects were also administered the investigator-designed Developmental Disabilities Attitudes Measure (DDAM) in order to more deeply probe their attitudes toward abortion in the context of disabilities. This four-point Likert scale comprises two sequentially

administered sorting tasks. The first assesses the *degree of concern* elicited by the description of a variety of disabling conditions with which a baby might be born. The second assesses the participant's hypothetical *willingness to terminate* a pregnancy for those same conditions. Two scores are calculated for each subject. One is the mean of all responses on the *level of concern* scale (4.0 = extreme concern; 1.0 = slight or no concern); the other is the mean of all responses on the *willingness to terminate* scale (4.0 = definitely willing to terminate; 1.0 = definitely would not terminate). (See Appendix C for details on the administration and content of the DDAM. See Press and Browner [1997a] for a longer discussion of DDAM results in the context of subjects attitudes toward disability.)

RESULTS

Table I presents the variables on which information was collected in each sample, as well as demographics of those who accepted and declined testing in both the MCS and QS.

The MCS contained 595 women, of whom 76% accepted the MSAFP test and 24% declined. Although the ethnicity categories we used were not precisely the same as those used by the Federal Bureau of the Census, the demographic breakdown of our population is roughly comparable to Census figures from Los Angeles county in 1994 [Los Angeles County, 1994; in that year, "whites" accounted for 37% of the population, "Hispanics" were listed as 41%, "blacks" were 10%,

TABLE I. Composition and Variables: Medical Chart Sample and Qualitative Sample^a

	Medical chart sample N = 595		Qualitative sample N = 158	
	Number	Percentage	Number	Percentage
MSAFP test decision				
Acceptors	452	75.9	127	80.4
Refusers	143	24.1	31	19.6
Ethnicity				
European-American	184	31.0	83	52.5
English-speaking Latina	167	28.1	55	34.8
Spanish-speaking Latina	131	22.0	20	12.7
African-American	65	10.9	—	—
Asian	37	6.2	—	—
Other	11	1.8	—	—
Socioeconomic status				
Middle	—	—	86	54.4
Lower	—	—	72	45.6
Religion				
Catholic	—	—	117	74.0
Non-Catholic Christian	—	—	41	26.0
Religiosity (Catholic and Protestant Religiosity Scales)	—	—		*
Reproductive History				
Age at first pregnancy		*		*
Number of previous pregnancies		*		*
Number of live births		*		*
Number of miscarriages		*		*
Number of induced abortions		*		*
Level of acculturation (Marin Acculturation Scale)	—	—		*
Concern about various disabilities (Development Disabilities Attitude Measure)	—	—		*
Willingness to abort for various disabilities (Development Disabilities Attitude Measure)	—	—		*

^a*, variable collected in this sample; — variables not collected in this sample.

Asian/Pacific Islanders were 11%, and less than 1% were listed as Native American].

The QS consisted of 158 women, 80% of whom accepted the test and 20% of whom declined. Forty percent of the non-Catholic Christians identified themselves as “born-again” Christians, and two-thirds of those had converted as adults, rather than being raised in a fundamentalist denomination. Results from the MCS and the QS will be discussed separately below.

MCS

Replicating the results of other researchers, we found no significant association between number of previous pregnancies, number of spontaneous miscarriages, or number of live births and a woman’s decision to accept or decline MSAFP testing.

Unlike other researchers, we did find an association between ethnicity and test refusal ($P = 0.001$). However, this effect was significant only in the case of Spanish-speaking Latinas, who were almost twice as likely to refuse testing as the rest of the sample ($P < 0.003$; odds ratio = 1.94).

We also found that women who had never terminated a pregnancy were significantly more likely to have refused testing ($P < 0.038$). This is consistent with the general assumption that objection to abortion is a strong factor motivating women to refuse prenatal testing [Faden et al., 1987; Baskin, 1983; Green et al., 1993]. However, in our sample, this association was mediated by a woman’s ethnicity.

Women in different ethnic groups were not equally likely to have ever had an abortion. Whereas 32% of the entire sample had previously terminated a pregnancy, the figures by ethnic group were widely dispersed; 53% of African-American women, 42% of European-American women, 29% of English-speaking Latinas, 19% of Asian-American women, and 15.5% of Spanish-speaking Latinas had previously had an abortion. Thus, whereas European-American and African-American women were significantly *more likely* than the rest of the MCS to have terminated a pregnancy, Spanish-speaking Latinas were more than three times *less likely* than the rest of the sample to have done so ($P < 0.00$).

Yet, when the combined effect of ethnicity and abortion history on test decision was examined, abortion history was found to predict test decision only for English-speaking Latinas, but not for the other groups. When English-speaking Latinas were divided into two groups, those who had terminated a pregnancy and those who had not, those with no history of abortion were 3.47 times more likely to have refused testing ($P < 0.017$).

Although not reaching levels of significance, we found several other interesting trends in the interaction of ethnicity, abortion history, and test decision. Although one could expect that abortion history and test decision would covary (e.g., higher rates of abortion would correlate with higher rates of test acceptance; lower rates of abortion would correlate with lower rates of test acceptance), the trends in our data suggest that this is not uniformly true across ethnic

groups. Thus, we found that African-Americans, who had the highest rates of pregnancy termination (53.1% had terminated a pregnancy), did not have high rates of test acceptance, but rather the second lowest rate of test uptake (70.0% accepted). Conversely, Asian-Americans, although unlikely to have ever had an abortion (18.9% had terminated a pregnancy), did not have low rates of test acceptance (81.0% accepted). See Table II for these data on all ethnic groups.

QS

As in the MCS, we found no significant association between a woman’s current age, age at first pregnancy, number of previous pregnancies, number of miscarriages, or number of live births and MSAFP test decision. Neither was social class significantly related to test acceptance or refusal.

Close to 100% of the women in the sample had an ongoing relationship with the biological fathers of their fetuses. Whether or not they were legally married was highly confounded with social class. However, the presence or absence of a male partner did not appear to influence test decision.

Approximately one-half of the sample (52%) reported having personally known someone with a disability. This category included a child, partner, parent, sibling, relative, close friend, or the woman herself, but did not include acquaintances. Relationship with someone with a disability was not a significant predictor of test decision.

Information retained about the MSAFP test was quite low. The average AFP Knowledge Score was 17.5 out of a possible 44, or 40% correct. However, we found no significant difference between mean test scores of acceptors and refusers. [For more information on the relationship of sociodemographics factors to information retained about MSAFP, see Browner et al. (1996)]. We also found that despite the low objective level of knowledge, the women in our sample were very likely to be satisfied with the amount of information they had been given about the test by their health care providers. Eighty-five percent of the total sample were satisfied, with information received seeming equally adequate to those who accepted and those who refused testing.

However, those women who refused MSAFP testing were significantly more likely than those who accepted to answer affirmatively to the interview question *When you were offered the AFP test did you have to think a lot about it before you made a decision?* ($P < 0.025$). Those who refused testing were also significantly more likely

TABLE II. Relationship of Abortion History to MSAFP Test Refusal by Ethnicity (Medical Chart Sample)

	Percentage who had ever terminated (Average for entire sample = 31.6%)	Percentage who refused MSAFP test (Average for entire sample = 24.7%)
Spanish-speaking Latina	15.5	34.1
Asian-American	18.9	19.0
English-speaking Latina	28.7	24.4
European-American	41.8	16.0
African-American	53.1	30.0

to answer yes to the question *When you were offered the AFP test did you talk the matter over with anyone?* ($P < 0.012$).

The effects of religion and religiosity were complex. Religion per se did not predict test decision; women raised Catholic and Protestant were equally likely to refuse testing. However, some aspects of religiosity were significantly correlated with test decision, but only for the European-American sample. Among Catholic, European-American women, those scoring higher on the *religious background* sub-scale, which asked about such things as parochial school attendance, catechism, and Lenten observation, were significantly more likely to have refused testing ($P < 0.005$). For both Catholic and Protestant European-American women, those who scored as highly observant of *church teaching on reproduction*, which included agreement with religious teachings on birth control, abortion, when human life begins, and extramarital sex, were also significantly more likely than the rest of the sample to decline MSAFP testing (Catholics, $P < 0.003$; Protestants, $P < 0.008$). See Table III for mean scores of sub-scales by ethnic group.

Unlike in the MCS, ethnicity per se was not found to be a significant predictor of test refusal in the QS. However, there was a combined effect of ethnicity and acculturation in the case of Spanish-speaking Latinas. The women in this group who scored as less acculturated on the Marin Short Acculturation Scale were significantly more likely ($P < 0.015$) than more acculturated Spanish-speaking Latinas to refuse testing. Among English-speaking Latinas, acculturation score did not predict test decision.

In our interviews, the Spanish-speaking Latinas who refused MSAFP testing talked about it in ways that were different from other refusers. Whereas most other refusers had a strong degree of objection to the test itself, for many Spanish-speaking Latinas testing simply seemed not to be relevant to their pregnancy. They often had little to say about why they had refused and appeared less to have rejected, objected to, or disliked the test than to have avoided it. It was not unusual for such women to have happened to miss the medical appointment at which a test decision would have to have been made. For the Spanish-speaking Latinas who did

articulate a specific objection to testing, fear of amniocentesis was often crucial to the decision to refuse. Moreover, they were more likely than any other women to either confuse MSAFP with amniocentesis or to be convinced that one led inevitably to the other. These refusers expressed a deep aversion to both the procedure and the risk of amniocentesis.

To examine the relationship of abortion to test decision across ethnic and religious groups, we looked at three aspects of abortion attitude and behavior: (1) women's self-reported history of abortion; (2) answers to the interview question, *Would you ever terminate a pregnancy for any reason?*; and (3) responses to the DDAM card-sort task, which assessed hypothetical willingness to terminate a pregnancy for particular disabilities. Each showed statistically significant effects.

As in the MCS, we found that history of induced abortion was a significant predictor of test decision. Women who had never terminated a pregnancy were significantly more likely than women who had terminated to refuse MSAFP testing ($P < 0.002$). Although in the QS, as in the MCS, Spanish-speaking Latinas were significantly less likely to have ever had an abortion than English-speaking Latinas or European-Americans, the sample was too small to assess the relationship among ethnicity, abortion history, and test decision in the QS.

We also found that attitudes toward abortion correlated with test decision in the QS. Women who said they would never terminate a pregnancy for any reason were significantly more likely ($P < 0.005$) to have refused testing than those who could imagine some situation in which they would or might end their pregnancy. Because most respondents could think of some reason, such as rape, incest or danger to the life of the mother, which could hypothetically motivate them to abort a pregnancy, the women who responded to this question in the negative were the women most adamantly against termination.

Abortion attitudes as measured by the DDAM were also found to be significant predictors of test decision. The question here was more directed than the open-ended query about hypothetical willingness to terminate and thus more clearly relevant to the sorts of decisions women would be asked to make following a posi-

TABLE III. Religiosity Scales by Ethnicity and Test Decision: Catholic Scale

Group	Sub-scale 1 Religious background		Sub-scale 2 Religious practice		Sub-scale 3 Religious belief		Sub-scale 4 Reproductive morality	
	Acceptors	Refusers	Acceptors	Refusers	Acceptors	Refusers	Acceptors	Refusers
	European Americans	2.58*	3.71	2.29	3.12	2.99	3.80	2.11**
English-speaking Latinas	2.88	2.78	2.79	2.50	3.23	3.32	2.33	2.54
Spanish-speaking Latinas	3.12	3.29	3.24	3.15	3.45	3.31	3.06	3.00
All Catholics	2.87	3.15	2.78	2.87	3.24	3.41	2.50	2.79

Group	Sub-scale 1 Religious practice		Sub-scale 2 Religious belief		Sub-scale 3 Reproductive morality	
	Acceptors	Refusers	Acceptors	Refusers	Acceptors	Refusers
	European-Americans	3.58	4.00	2.59	2.95	2.89***

* $P < 0.005$; ** $P < 0.003$; *** $P < 0.008$.

tive MSAFP test result. We found that those respondents who answered that they *would definitely not terminate* their pregnancy for *any* of the conditions in the DDAM were significantly more likely than the rest of the sample to be test refusers ($P < 0.002$).

When we examined these three markers of relationship to abortion (personal history, interview question about willingness to terminate, and DDAM responses) for just that group of women who refused testing, we found abortion history to be the best predictor of test refusal. This was true for all ethnic groups combined and for each ethnic group examined separately. Table IV summarizes which variables were found to be significant in the MCS and QS.

DISCUSSION

We found ethnicity, religiosity, and attitudes and actions in regard to abortion to be significant in predicting the likelihood that a woman would refuse an offer of MSAFP testing. However, we found these variables to be related in complex ways.

The Association Between Ethnicity and Test Refusal

Ethnicity has been found to be an important predictor of the utilization of health care services in general [Waitzkin, 1983; Mechanic, 1986; Brown, 1989]. However, ethnicity in itself is little more than an “address” variable: Knowing that a certain ethnic group behaves

in a certain way does not tell us what aspect of culture explains this behavior or even whether it is culture, rather than some contingent sociodemographic variable, such as social class, that is causal. Thus, in the MCS, the reason that Spanish-speaking Latinas were more likely to refuse testing is unknown. However, in the QS, the greater likelihood to refuse testing among Spanish-speaking Latinas could be clarified. Differences in acculturation scale scores within the Spanish-speaking Latina sample and the association of lesser acculturation with a greater likelihood to refuse testing indicated that there may indeed be aspects of traditional Latina culture that are antithetical to accepting prenatal diagnosis. Data from our interviews with Spanish-speaking refusers, which revealed a different way of talking about MSAFP, further support this view.

It is not clear why differences in acculturation, as measured on the Marin Short Acculturation Scale, did not predict test decision for the English-speaking Latinas. However, level of acculturation is determined on this scale primarily by English language use in a variety of situations. For the English-speaking Latinas who, by our definition, were comfortable with the use of English, this scale did not appear to be sufficiently sensitive to detect differences among second-generation Latinas on the variables relevant to this study.

The Association Between Religiosity and Test Refusal

The absence of any effect of religiosity for the Latina groups was unexpected, because the importance of Catholicism to Latino populations is generally assumed, as is the influence of Catholic belief on attitudes and practices in regard to reproductive morality (Amaro, 1988). In our study, religiosity was associated with MSAFP test decision only for the European-American sample. Although our data provide no definitive reason for this difference, it is possible that Latinas have a more contingent affiliation to the Catholic Church than do European-Americans. That is, it may be that being raised Catholic is so much a part of Latino culture that responses on the religiosity scale merely reflect learned, culturally appropriate responses rather than belief that would guide behavior. If this supposition is correct, it would also suggest why scores on the *religious background* sub-scale were significantly correlated with test decision for European-American, Catholic women but not Latinas: for European-American women, being raised in a strong Catholic tradition in the midst of a largely Protestant mainstream culture may imply a more marked commitment to specific Church teachings than is the case for Catholic Latinas.

Scores on the *Church teachings on reproduction* sub-scale correlated with test refusal for European-American women, both Catholic and Protestant. The logic here is more straightforward, because questions on birth control and abortion were prominent in this sub-scale. For Protestant women who refused, *Church teachings on reproduction* was the only significant sub-scale; the *religious background* sub-scale did not predict test decision for Protestant women as it did for Catholic European-Americans. It is possible that this is

TABLE IV. Predictors of Test Refusal*

Sample	P value
Medical chart	
Age	NS
Ethnicity ^a	0.001
Number previous pregnancies	NS
Number of miscarriages	NS
Number of live births	NS
Number of induced abortions	0.038
Qualitative	
Age	NS
Ethnicity ^a	NS
Number previous pregnancies	NS
Number of miscarriages	NS
Number of live births	NS
Number of induced abortions	0.002
Would not terminate for any reason	0.005
DDAM	0.002
Age at first pregnancy	NS
Level of education	NS
Socioeconomic status	NS
Religious background	NS
Religiosity ^b	0.005
Level of acculturation (Spanish-speaking Latinas only) ^c	0.015
Amount of information retained about MSAFP test	NS
Think much before decision	0.025
Talk to someone before decision	0.012

*NS, not significant.

^aThere was insufficient sample size for Spanish-speaking Latinas in this sample for a reliable result.

^bOnly scores on the *Church Teaching on Reproduction* sub-scale were significant.

^cOnly within the Spanish-speaking Latina sample was acculturation level and test decision significantly correlated.

because almost all of the Protestant women who refused testing categorized themselves as fundamentalist Christians and almost all of them had come to their current religious beliefs as adults. It is worth noting that it was only among Protestant women who refused testing that we heard the sort of argument that fits the popular image of a prenatal test refuser: a discourse that connects prenatal testing directly with abortion and premises test refusal specifically on a moral objection to terminating a pregnancy.

The Association Between Abortion History and Attitudes and Test Refusal

Few other studies of MSAFP decisions have looked at actual abortion behavior, but one that did [Berne-Frommel et al., 1984] found no connection between a woman's own abortion history and test refusal. We suspect this may be due to the fact that this relationship is so highly mediated by ethnicity. This is suggested in our data by the counterintuitive trend between abortion history and test decision in the Asian-American and African-American samples. Although we have no qualitative data from these two groups of women, it seems likely that it is not attitude toward abortion that is driving test refusal among African-Americans, since they are the group most likely to have a personal history of abortion. Conversely, the high acceptance rates and low abortion rates seen in the Asian-American population could, hypothetically, be explained by other factors, such as a strong wish to have many children [Hahn and Muecke, 1987], and may not reflect either negative attitudes toward abortion or positive attitudes toward prenatal testing.

Attitudes toward, as well as personal history of, abortion were also predictive of test refusal. This, again, is not unexpected. Therefore, it is worth noting what our data did *not* say about the connection between abortion and MSAFP test decision. Although abortion attitudes and behavior appear to be an effective way to predict a significant number of the women who will refuse testing, it is important to note that more than 60% of those women who refused MSAFP testing admitted the possibility of terminating a pregnancy for at least one disabling condition. Thus, more than half of the refusers *could* imagine a circumstance that would lead them to have an abortion. Conversely, it is also important to note that fewer than 15% of test *acceptors* said that they would have terminated their pregnancy if all prenatal test results had confirmed a fetus with a disability. Thus, although negative attitudes toward abortion were more common among women who refused, the statistical significance of this finding should not obscure the fact that many of those who accepted held similar views. Therefore, although a negative attitude toward abortion may be an important predictor of refusal, one cannot conversely assume that acceptance means a positive attitude toward pregnancy termination.

Even strong personal objection to abortion was not always sufficient to lead a woman to refuse testing; many women who accepted testing revealed themselves in the interview to be uncategorically opposed to abortion. But, as we have discussed elsewhere [Press

and Browner, 1993], the connection between abortion decision-making and MSAFP testing was consciously and assiduously downplayed at the HMO and in the educational material given to pregnant patients. Thus, it may be necessary for women to come into prenatal care already sensitized to the connection between prenatal testing and abortion in order for abortion attitudes to become activated as part of an MSAFP testing decision. For example, women who were members of fundamentalist Christian congregations frequently stated they had been aware before beginning prenatal care that they might be offered prenatal diagnosis and that they had always intended to refuse testing; they had been explicitly taught that prenatal diagnosis was predicated on the option of pregnancy termination.

This lack of complete fit between abortion attitudes and test decision should, therefore, be especially common if there are structural factors in the health care setting that push for test acceptance. As we have discussed elsewhere [Press and Browner, 1993; Browner and Press, 1995], in the HMO where we collected our data, MSAFP testing was very much routinized as part of the standard prenatal care package. We think this is why women who had refused testing were significantly more likely to answer affirmatively to both our questions (*When you were offered the AFP test, did you have to think a lot about it before making a decision?* and *Did you talk the matter over with anyone before deciding?*). It would appear, in other words, that test refusal was the marked or unusual case—not just statistically, but experientially as well. Perhaps in such a context, only those women with the most definite and negative attitudes toward abortion refuse. Interesting support for this interpretation is provided by Sikkink [1990]. In that study, those women who *accepted* MSAFP screening were the ones more likely to have consulted a significant other about the test decision. However, in the medical setting in which Sikkink worked, test *acceptance* was the unusual decision, with only 31% of women consenting to be screened.

CONCLUSIONS

This research is limited by the construction of the samples. The QS was designed to elicit rich narrative accounts of the experiences and meaning MSAFP screening has to women in the course of their pregnancies. The MCS helped add statistical power to some inquiries but could not provide information on all the variables of interest, specifically religiosity and acculturation, variables that appear to play an important part in women's test decisions. Thus, it was not possible to place abortion history, ethnicity, acculturation, and religiosity into a multiple logistic regression analysis. It is possible that such an analysis could provide a unitary model of the relationship of these factors.

Although our data provide support for the presumption that prenatal test refusal is related to attitudes toward abortion, we believe that our more important findings actually reflect on the limitations of that connection. Specifically, our data suggest that, while test refusal may correlate with negative attitudes toward abortion, test acceptance should not be construed as

implying positive attitudes toward the possibility of terminating a pregnancy for a fetal anomaly. Our body of work in observing the implementation of the MSAFP program at this HMO (Press and Browner, 1993, 1994, 1995, 1997a) would strongly suggest that the relationship of abortion attitudes and test decision is mediated by the meaning of the test decision, which will itself be shaped more by the structure of the medical setting than by the views of individual women. Thus, in a setting in which test acceptance is encouraged, many test acceptors will share negative attitudes toward abortion with test refusers. In addition, although test refusers may, on average, hold more negative views on pregnancy termination, these attitudes will be nuanced and should not be read as a total rejection of the possibility or actuality of abortion in all situations. Ultimately, although the test decision is binary, the paths leading to it are diverse. Predicting which women will refuse may be far less useful than understanding the interaction of factors, including ethnicity, religiosity, and medical setting, which shape the meanings of the prenatal test decision for individual women.

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APPENDIX A: CATHOLIC RELIGIOSITY SCALE

This 31-question scale was composed of four sub-scales. The questions are listed below according to the sub-scale to which they belong. The number to the left of each question indicates its position in the scale as it was administered.

Sub-Scale 1: Religious Background

1. Did you go to Catholic elementary school?
 - a. I did not attend Catholic elementary school
 - b. I attended Catholic school for some of my elementary school years
 - c. I attended Catholic school for all grades until high school
2. Did you go to Catholic high school?
 - a. I did not attend Catholic high school
 - b. I attended Catholic high school for some of my high school years
 - c. I attended Catholic high school for all four years
3. Did you go to catechism classes at times when you weren't going to Catholic schools?
 - a. All my schooling was in Catholic schools
 - b. Always
 - c. Sometimes
 - d. Never
4. How often did you attend Mass as a child?
 - a. Just about daily
 - b. Just about every week
 - c. Once every one to two months, we went when we could
 - d. Only on special occasions, such as Easter, Christmas, weddings
 - e. Almost never
5. Were you confirmed (Did you receive Confirmation)?
 - a. Yes
 - a. No
6. How did you usually observe Lent?
 - a. I usually fasted on all or most days of Lent
 - b. I usually gave up something I liked for Lent
 - c. I occasionally fasted or gave up something that I liked for Lent
 - d. I rarely fasted or gave up something that I liked for Lent
 - e. I never or almost never observed Lent

30. Were your parents practicing Catholics?
 - a. Both my parents were practicing Catholics
 - b. Only one of my parents was a practicing Catholic
 - c. Neither of my parents were practicing Catholics

Sub-Scale 2: Current Religious Practice

7. Do you consider yourself a Catholic now?
 - a. Yes
 - b. No
10. Would you discuss questions about family planning with a priest?
 - a. Yes, if I had questions I would go to any priest
 - b. Yes, but I would try to find a priest who is sympathetic to my views on these issues
 - c. No, I don't think a priest would give me useful advice on family planning issues
11. Would you discuss questions about other sorts of family or spiritual issues with the priest?
 - a. Yes, if I had questions I would go to any priest
 - b. Yes, but I would try to find a priest who is sympathetic to my views on these issues
 - c. No, I don't think a priest would give me useful advice or understand my situation
16. How often do you attend confession?
 - a. Regularly
 - b. At least once a year
 - c. Almost never
19. How often do you attend Mass?
 - a. Daily or almost daily
 - b. Once a week
 - c. I go as often as I can
 - d. Only on special occasions, such as Easter, Christmas, weddings
 - e. Almost never
22. Do you currently attend a particular Church on a regular basis?
 - a. Yes
 - b. No

Sub-Scale 3: Religious Belief

8. I believe that health is sometimes sent by God.
 - a. Strongly agree
 - b. Agree
 - c. Uncertain
 - d. Disagree
 - e. Strongly disagree
9. I try to act in a Christian way in all my dealings with people.
 - a. Strongly disagree
 - b. Disagree
 - c. Uncertain
 - d. Agree
 - e. Strongly agree
12. What do you think makes it likely that someone

- will go to Heaven when they die?
 a. I believe that those who die in a state of grace will join God in heaven
 b. I believe that any person who has led a good life will go to heaven
 c. I don't believe there is a heaven
13. I believe that sickness is sometimes sent by God.
 a. Strongly agree
 b. Agree
 c. Uncertain
 d. Disagree
 e. Strongly disagree
14. I consider myself to be a religious person.
 a. Strongly disagree
 b. Disagree
 c. Uncertain
 d. Agree
 e. Strongly agree
17. How frequently do your religious beliefs enter your thoughts?
 a. Almost never
 b. Generally when there is a problem or difficulty in my life
 c. Occasionally
 d. Frequently, probably at least once a week
 e. Almost every day
18. When I have a decision to make in my life I look to the Church for guidance in choosing the right path.
 a. Always
 b. Frequently
 c. Occasionally
 d. Rarely
 e. Never
21. How often do you pray?
 a. Several times a day
 b. Almost every day
 c. At least once a week
 d. Occasionally
 e. Almost never
- b. I try to follow it in principle, but I don't follow it completely
 c. Yes
25. The Church teaches that human life begins at the moment of conception. What is your opinion of this Church teaching?
 a. I agree with this Church teaching
 b. I'm not certain
 c. I do not agree with this Church teaching
26. The Church teaches that only married couples should have sexual intercourse. What is your opinion of this Church teaching?
 a. I am in full agreement with this Church teaching
 b. I agree in principle with this Church teaching, but I think it is too strict and not completely realistic in today's world
 c. I largely or completely disagree with this Church teaching
27. In your own life, have you followed the Church's teachings on premarital and extramarital sex?
 a. No
 b. I have tried to follow it in principle, but I haven't followed it completely
 c. Yes
28. The Church teaches that there is absolutely no circumstance under which abortion is justified. What is your opinion of this Church teaching?
 a. I am in agreement with this Church teaching
 b. I'm not certain
 c. I do not agree with this Church teaching
29. In your own life, have you followed the Church's teaching on abortion?
 a. No
 b. I have tried to follow it in principle, but I haven't been able to follow it completely
 c. Yes

Sub-Scale 4: Reproductive Morality

20. The Church teaches that the Pope cannot make mistakes when he makes statements about faith and morals. What is your opinion about this Church teaching?
 a. I disagree with this Church teaching
 b. I am uncertain about this Church teaching
 c. I agree with this Church teaching
23. The Church teaches that the only acceptable form of preventing or avoiding conception is natural family planning (the "rhythm" method). What is your opinion of this Church teaching?
 a. I am in full agreement with this Church teaching
 b. I agree in principle with this Church teaching, but I think it is too strict and not completely realistic in today's world
 c. I largely or completely disagree with this Church teaching
24. In your own life, do you follow the Church's views on birth control as described above?
 a. No

APPENDIX B: PROTESTANT RELIGIOSITY SCALE

This 31-question scale was composed of three sub-scales. The questions are listed below according to the sub-scale to which they belong. The number to the left of each question indicates its position in the scale as it was administered.

Sub-Scale 1: Religious Practice

1. In what religion were you raised? (Please write answer below) [Note: This question is not scored. It simply provides background, demographic information.]
2. Do you still consider yourself a member of that religion?
 a. Yes
 b. No
3. How often did you attend Church as a child?
 a. Just about daily
 b. Just about every week
 c. Once every one to two months, we went when we could
 d. Only on special occasions, such as Easter and Christmas

- e. Almost never
- 4. How often do you currently attend Church?
 - a. Just about daily
 - b. Just about every week
 - c. Once every one to two months, I go when I can
 - d. Only on special occasions, such as Easter and Christmas
 - e. Almost never

Sub-Scale 2: Religious Belief

- 5. I believe that one should seek God's guidance when making every important decision.
 - a. I agree strongly
 - b. I agree
 - c. I disagree
 - d. I disagree strongly
- 6. My faith sometimes restricts my actions.
 - a. I agree strongly
 - b. I agree
 - c. I disagree
 - d. I disagree strongly
- 7. In my life I experience the presence of the Divine.
 - a. I agree strongly
 - b. I agree
 - c. I disagree
 - d. I disagree strongly
- 8. My faith involves all of my life.
 - a. I agree strongly
 - b. I agree
 - c. I disagree
 - d. I disagree strongly
- 9. Although I am a religious person, I refuse to let religious considerations influence my everyday affairs.
 - a. I agree strongly
 - b. I agree
 - c. I disagree
 - d. I disagree strongly
- 10. Nothing is as important to me as serving God as best I know how.
 - a. I agree strongly
 - b. I agree
 - c. I disagree
 - d. I disagree strongly
- 11. It doesn't matter so much what I believe as long as I lead a moral life.
 - a. I agree strongly
 - b. I agree
 - c. I disagree
 - d. I disagree strongly
- 12. I try to carry my religion over into all my other dealings in life.
 - a. I agree strongly
 - b. I agree
 - c. I disagree
 - d. I disagree strongly
- 13. My religious beliefs are what really lie behind my whole approach to life.
 - a. I agree strongly
 - b. I agree
 - c. I disagree
 - d. I disagree strongly
- 14. Although I believe in my religion, I feel there are many more important things in life.
 - a. I agree strongly
 - b. I agree
 - c. I disagree
 - d. I disagree strongly

Sub-Scale 3: Reproductive Morality

- 15. Some religions teach that any "artificial" means of birth control (such as birth control pills or condoms) is unacceptable. They say that the only acceptable form of preventing or avoiding conception is natural family planning (the "rhythm" method). What is your opinion of this view?
 - a. I am in full agreement with this view
 - b. I agree with this in principle, but I think it is too strict and not completely realistic in today's world
 - c. I largely or completely disagree with this view
- 16. Which statement best describes your own practices in regard to birth control?
 - a. I agree that natural family planning (the "rhythm" method) is the only morally acceptable form of birth control *and* I follow this view in my own life
 - b. I agree that natural family planning (the "rhythm" method) is the only morally acceptable form of birth control, *but* I cannot always follow this strict rule in my own life
 - c. I do not consider birth control a moral issue. My husband (boyfriend) and I would use any means of birth control that we find convenient
- 18. Many religions teach that only married couples should have sexual intercourse. What is your opinion of this view?
 - a. I am in full agreement with this view
 - b. I agree in principle with this view, but I think it is too strict and not completely realistic in today's world
 - c. I largely or completely disagree with this view
- 19. In your own life, have you followed the above-stated religious view on premarital and extramarital sex?
 - a. No
 - b. I have tried to follow it in principle, but I haven't followed it completely
 - c. Yes
- 20. Some religions teach that there is absolutely no circumstance under which abortion is justified. What is your opinion of this?
 - a. I am in agreement with this view
 - b. I'm not certain
 - c. I do not agree with this view
- 21. In your own life, have you followed this religious teaching on abortion?
 - a. No
 - b. I have tried to follow it in principle, but I haven't been able to follow it completely
 - c. Yes

APPENDIX C: DDAM

The DDAM comprises two sequentially administered sorting tasks. Each task requires the subject to sort the same set of cards on which are written, one to a card, the symptoms of 17 disabling conditions that can be genetically transmitted. The first task requires sorting the cards according to the degree of concern the subject would experience if told that her fetus would be born with the condition characterized by the symptom on each card. Cards can be placed under one of four headings: *Extreme Concern*, *Considerable Concern*, *Mild Concern*, or *Slight or No Concern*. The second task asks the subject to sort the cards according to her hypothetical willingness to terminate her pregnancy if she were told that the fetus would be born with the condition characterized on each card. Cards can be placed under one of four headings: *Would Definitely Terminate*, *Would Probably Terminate*, *Would Probably Not Terminate*, and *Would Definitely Not Terminate*. The cards are shuffled before each task, so that card order is not the same from task to task or subject to subject.

The symptoms listed on the 17 cards are given below. Each card begins with the words *A condition which . . .*

1. leads to death in one's 20s
2. always causes death within days or weeks of birth
3. causes quadriplegia (paralysis from the neck down)
4. may cause behavior problems in the child (such as excessive aggressiveness)
5. will make the individual sterile—unable to have children
6. causes episodes of very severe illness throughout the individual's life
7. causes paraplegia (paralysis from the waist down)
8. causes mild mental retardation with unusual appearance
9. causes mild retardation with normal appearance
10. leads to death before age 5
11. causes physical deformity
12. causes total deafness
13. causes severe mental retardation
14. leads to blindness in adulthood
15. causes total blindness
16. causes some hearing loss
17. makes it likely that an individual will have heart disease or cancer as an adult