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LATINAS, AMNIOCENTESIS AND THE DISCOURSE OF CHOICE

ABSTRACT. Little attention has been paid to the impact of the increasingly routine use of fetal diagnosis on how U.S. minority women experience their pregnancies and decide whether to have their fetuses tested. Using narrative analysis, we offer the account of one Latina who, despite considerable turmoil, ultimately accepted an offer of amniocentesis. We describe her reasoning in choosing a course of action. Data from interviews with 147 Latinas who were faced with the same decision are used to contextualize the case study material. We seek to illuminate how a blending of Mexican and European American cultural influences helped shape the woman's experience and define the dilemma she faced when she learned her fetus might be born with a grave or incurable condition because she was ideologically opposed to abortion.

INTRODUCTION

Fetal screening for birth anomalies through routine use of a blood test which measures the maternal serum alpha-feto protein excreted by the fetus has become widespread in most industrialized societies (Evans et al. 1993; Meaney et al. 1993; Santalahti et al. 1998; Wald et al. 1992). Yet the extent and speed of its acceptance has surprised many bioethicists and advocates for women's health (Abramsky and Chapple 1994; Rothenberg and Thomson 1994). For instance, in the state of California in 1996, nearly 70% of pregnancies were screened, up from 42% only ten years beforehand (Cunningham 1998). Women whose test results are negative, or normal, typically report that their experience was unproblematic. Most say that learning that their fetus has no detectable anomaly is valuable, reassuring, and worth the anxiety they may have felt while waiting several days for the test results (Kolker and Burke 1994; Marteau et al. 1992).

Screening positive, however, which may indicate the possibility of a developmental defect, can precipitate a crisis: the threat of a birth anomaly; the prospect of an invasive amniocentesis and its discomfort, risk of fetal injury, and possibility of miscarriage; and the need to decide whether to have a second-trimester abortion should the amniocentesis detect an anomaly produce intense anxiety in many women (Green 1990).[1] Yet screening positive is by no means rare: seven to 13 percent of women do

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so (Burton et al. 1985; Cunningham 1998; Evans et al. 1987; Greenberg 1988).[2] This is an artifact of medical protocol that enables laboratories to detect the maximum number of true positives by including a high percentage of false in the screening procedure. But what is medically reassuring may be extremely anxiety provoking from the pregnant woman's point of view.

Most research on women's experiences with fetal diagnosis has focused on those at high risk for bearing a child with an anomaly due to advanced maternal age, prior reproductive problems, or known family risk. Much of what we know, then, about the experience of fetal diagnosis comes from a population of women already concerned about their ability to bear a healthy child. The women in these studies have also been overwhelmingly middle class, urban, well-educated, and European or European American (Nsiah-Jefferson 1993; Rapp 1993). In contrast, far less attention has been paid to ethnic minority women and to the ways ethnicity might shape their experiences with and decisions about fetal diagnosis (Mittman et al. 1998; Ota Wang 1998).

Do women from other than European American backgrounds respond differently to the offer of screening or further diagnostic tests? Our ongoing research with low income and working class women of Mexican backgrounds in southern California suggests that they often make choices about prenatal diagnostic testing which are the same as the middle class European American women whose medical decisions have been much more extensively studied and reported. But we contend that Latinas may make similar choices for different reasons. To illustrate these similarities and differences, we present the narrative account of one Latina, who, despite experiencing considerable confusion and turmoil upon learning she had screened positive, ultimately accepted the invasive amniocentesis procedure. We focus on her reasoning in choosing a course of action. Material from a larger set of interviews with 147 Latinas who also screened positive and faced the same decision is drawn upon to provide bases for comparison.

We chose to present the in-depth analysis of a single case for the light it can cast on how specific circumstances can lead to a particular outcome (Becker 1997; Denzin 1989). Such analyses contrast with quantitative approaches which offer insight into general patterns, but tend to provide limited insight into those who fall outside the generalizable patterns observed. In the case study below, we detail the considerations that led the woman we call Isabel to reluctantly agree to amniocentesis and seek to show how the blend of her Mexican and European American

backgrounds shaped not only her decision but the means by which she arrived at a course of action.

It is important to note that characterizing Isabel's act as a 'decision' significantly overstates the degree of intentionality in her behavior, for the course she ultimately embarked on was less a single large decision than a series of less profound incremental steps (Hunt et al. 1998; Ryan 1998). Therefore, throughout this account we tend to use the term 'course of action' rather than 'decision'. In this regard, our data are not unique. Rothman similarly found that whether or not to have amniocentesis was experienced as a conscious decision to widely varying degrees by the women with whom she worked. She writes, "One can simply show up for all scheduled doctor's appointments and have the amnio without any more experience of decision-making than attends, say, the routine blood tests and urinalysis of pregnancy management. Or, conversely, one can just 'do nothing'," … without having made a deliberate decision (Rothman 1987: 51).

We show that an extensive network of resources within Isabel's family, church, and neighborhood, as well as within her biomedical community, seemed to help propel her forward, although not in a linear direction, for she was given inconsistent and even contradictory advice and information. As a result, she found herself caught between the promise of reassurance that a negative, or normal, amniocentesis would offer and the criticism she expected she would endure within her own networks should she subject her fetus to the test's known risks. Representing herself as 'a victim of circumstances' who had 'no choice' but to agree to amniocentesis provided Isabel a means to extricate herself from this dilemma. Rationalizing her decision as being outside her own control enabled Isabel to follow clinical recommendations, gain information, and leave open the option of abortion, while acting according to what she regarded as maternally appropriate behavior.

Taylor's theory of cognitive adaptation, which describes the processes through which individuals come to terms with victimizing events, provides a productive framework for understanding the case material (Taylor 1983). Taylor shows that adaptation following a threatening experience involves three sets of concerns: the search for meaning, attempts to gain control, and efforts to rebuild self image. We seek to show that the narrative explanations women construct to account for the threat to their pregnancy embodied in an amniocentesis offer can facilitate re-adaptation (cf. Becker 1997). Taylor finds that it is not unusual for individuals to come to terms with threatening experiences by blaming their misfortune on external forces such as bad luck, malevolent intentions, or even witchcraft. The

narrative we discuss below shows this clearly. Like several others in the study, Isabel claimed that 'circumstances' had led her to a particular course of action, leaving open the possibility that had other circumstances presented themselves, the outcome would have been different. In fact, such rationalizations are often not far from reality (Markens, Browner and Press 1999).

METHODS AND BACKGROUND

The study was designed to investigate the factors associated with amniocentesis acceptance and refusal among southern California women from Latino backgrounds. We were particularly interested in the effects of acculturation because anecdotal reports indicated that recent Latina immigrants were more likely than U.S. born Latinas to refuse amniocentesis. Because local health care providers who work extensively with Latinas believe that social class, education, and abortion attitudes are predictive of amniocentesis refusal we examined these factors as well (Garcia 1995; Tatsugawa 1995, 1996).

Participants were recruited from six California state-approved Prenatal Diagnosis Centers where amniocentesis is offered to women at high risk for bearing a child with a birth defect. Our study focused only on women offered amniocentesis because they screened positive on the maternal serum alpha-feto protein (AFP) blood screening blood test, which is routinely offered in California as part of the standard package of prenatal care. Although the test is not mandatory, about three fourths of the women who are offered screening in fact agree to be tested (Browner and Press 1995; Press and Browner 1997, 1998).

California women who screen positive, which may suggest the possibility that the fetus is affected by a neural tube defect (an anomaly of the spine or brain), Down syndrome, or some other chromosomal abnormality, are referred for a genetic consultation and further testing at a state-approved Prenatal Diagnosis Center. While they are urged by their prenatal care providers to attend this no-cost consultation,[3] they are not obliged to do so. However, less than about 5% of all screen-positive women turn down the genetic consultation with its offer of additional information about their fetus's health (Garcia 1995; Tatsugawa 1995). The genetic consultation is conducted by a licensed provider with Master's level training in genetics and counseling techniques. During the approximately 45 minute session, the counselor obtains a reproductive and family history and offers information about the possible causes of the positive screen. This consultation is intended to be 'non-directive' (Harper 1993):

information is provided and questions are answered but counselors are trained not to make recommendations. In reality, however, the extent to which counselors consciously or unconsciously seek to influence clients' decisions, and the degree to which clients perceive counselors as directive, varies considerably (Browner and Preloran 1999), as will be seen in Isabel's case below.

At the conclusion of the genetic consultation, women are offered a high resolution (Level 2) ultrasound exam. Women rarely decline this test, mainly because it is considered risk-free and offers the hope of reassurance. In about half the cases, the ultrasound reveals a benign explanation for the positive screen, usually a misdated gestation. Occasionally a gross defect (e.g. anencephaly, severe Spina bifida) is found. In the remaining cases, the ultrasound is inconclusive and the woman is generally offered amniocentesis. Although most amniocenteses are normal, further counseling is offered to women whose amniocenteses reveal an anomaly, with the option of abortion through the 24th week of pregnancy.

We conducted face-to-face, semi-structured interviews of one to several hours duration with 147 Latinas who were offered amniocentesis because they had screened positive.[4] Sixteen percent were interviewed several times over the course of their pregnancies, while the remainder were interviewed just once. All participants were interviewed after they had made their decision about amniocentesis. Interviews were conducted in the participant's language of choice (either Spanish or English) by one of the two authors or a trained bilingual field assistant at a place and time of the participant's choosing. In the vast majority of cases, this was the participant's own home. Supplemental and follow-up information was obtained by telephone.

Interviews covered the following topics: background (including social class, ethnicity, religious background and current religious practice, access to economic resources, gender role attitudes, division of domestic labor); reproductive history and experience with current pregnancy; factors considered in the amniocentesis decision; extent of the male partner's participation in the woman's prenatal care in general and in the amniocentesis decision; the extent and nature of the woman's social support and the role others played in the amniocentesis decision; perceived influence of medical personnel; the woman's knowledge and attitudes about disability, prenatal diagnosis, induced abortion; level of comfort with amniocentesis decision and level of satisfaction with the clinical experience.

QUANTITATIVE FINDINGS

The 147 women ranged in age from 14 to 46 (mean 27.9, s.d. = 7.3). They reported an average of 2.01 previous pregnancies (range = 0–8; s.d. = 1.94). Forty-six of them (31.3%) reported miscarriages, with 73.9% (n = 34) reporting just one and the rest two to four. Twenty-five of 140 women (17.9%) reported one or more induced abortions; 84.0 percent reported one and others two or three. Fifteen of 145 (10.3%) said they had children who died (13 reported one and 2 reported two) and 10/144 (6.9%) said they had children born with anomalies.[5] There were no statistically significant differences between these reproductive characteristics and those of the 379 Latinas who were offered amniocentesis at the same genetics clinics during 1996. These latter data were obtained through a review of patient charts.

Sixty-nine percent of the women in the interview sample were born in Mexico and 31% in the U.S. Scores on the Marín Short Acculturation Scale (Marín et al. 1987) ranged from 12 to 56 out of a maximum of 60 (mean = 28.0; s.d. = 12.1).[6] Sixty-nine percent chose to be interviewed in Spanish and 31% in English. Twenty five point three percent reported only primary school education or less, 49.3% secondary or less, and 25.3% had studied beyond secondary school. Household income for 34.5% was less than $10,000 per annum and greater than $20,000 for 27.5%. Although 83.0% were Catholic, of those, only 16% reported attending Mass every Sunday and just 13% regularly went to Confession and took Communion.

All women agreed to the Level 2 sonagram; 60% of the women accepted the amniocentesis and 40% declined.[7] There were no significant differences between those who accepted and those who declined in age, education, household income, religious background or religiosity. Both groups of women had similar reproductive histories (i.e., numbers of 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 U.S. culture would be more likely to decline amniocentesis. This hypothesis received partial support. While women born in Mexico were more likely to turn down the procedure ($x^2 = 4.67$, $p = 0.031$), neither a woman's acculturation score nor length of time in the U.S. proved predictive.

Although, as hypothesized, women who declined amniocentesis were significantly more likely to describe themselves as strictly opposed to abortion ($x^2 = 13.99$, $p = 0.007$), the relationship between abortion attitudes and amniocentesis decisions proved complex. There was significant overlap between those who accepted and those who declined in their views on

abortion. Just over half of women who accepted said they would ever consider an abortion as did 26% of those who declined. The remainder of those who declined and fully 42% of those who accepted reported that abortion was personally unacceptable under all circumstances.

Because our quantitative results cast little light on what led some Latinas who were told their fetuses were at high risk for a birth anomaly to agree to amniocentesis and others to decline, we turned to the narrative accounts women gave of their decisions, one of which we will present here. We chose Isabel's for detailed analysis because she was representative of the larger sample with regard to standard sociodemographic variables such as age, household income and education. She was also typical in the range of emotional issues the positive screening test evoked. At the same time, she was one of our most articulate participants in her ability to verbalize how she felt and responded to the amniocentesis offer. She was also unusual in having been diagnosed with and successfully treated for breast cancer at the age of 24. She therefore had a more complicated medical history than most other women in our sample and much more experience with the biomedical system.

THE ANALYSIS OF AN AMNIOCENTESIS NARRATIVE

Narratives are stories typically told in casual conversation. They tend to follow a sequential structure and make a moral point (Reissman 1993; Cebik 1984). As interpretative devices, narratives offer explanations for why things happened as they did and what role the characters in the narrative played in bringing about a course of events in question. In recent years, narrative analysis has gained attention in the humanities and medical and social sciences for the insight it can provide into the meaning and experience of health, illness, healing, and recovery (Kleinman 1988; Bruner 1991; Mishler 1986; White 1980). Illness narratives have been shown to be particularly useful for understanding how individuals respond to threatening situations involving painful or otherwise difficult medical decisions (Becker 1997; Del Vecchio Good et al. 1994; Early 1982; Layne 1996; Rapp 1998; Saris 1995; Sobo 1997). Through stories which both articulate and mediate the disruption, narratives can help restructure a sense of self and social location (Becker 1997; Hunt in press; Riemann and Schutze 1991). Illness narratives reveal how constructions of the concrete and the personal are grounded in culture; they cast light on the role of individual experience in the creation of shared knowledge (Frankel et al. 1991). The relationship between narrative structure and experience, then, is a dialectic one (Bruner 1988; Mogensen 1997).

To analyze Isabel's amniocentesis narrative, we drew on both scheme analysis (D'Andrade 1991) and grounded theory (Glaser and Straus 1967) to create a totality from the scattered events Isabel recounted during our six hours of face-to-face interviews which occurred over the course of four meetings and ten telephone conversations. All conversations were tape recorded and transcribed. Three project researchers read all of the transcripts with two questions in mind: "What were the external and internal factors impinging upon Isabel as she tried to decide whether to have amniocentesis?" and "Which seemed most salient in her final decision to consent to the procedure?" After multiple readings, we agreed that the following six categories, grouped in approximate order of importance, illuminated these two questions: Isabel's belief that she had been cursed and her father's support, her experience with cancer and her previous induced abortion, her religious conversion and practice and her interactions with clinicians. As idiosyncratic as these categories might seem, they represent the issues that Isabel repeatedly emphasized throughout our multiple encounters. During our readings, we noted our reasons for coding each excerpt as we did and compared our notes until coding agreement was attained.

The pieces that we used to construct Isabel's narrative account were extracted chronologically from six of our fourteen encounters. The content derives from Isabel's explanations of how she decided to accept the amniocentesis, and why. As will be seen below, we found that Isabel frequently linked her answers to these questions to her genetic counseling experience.

We also drew on Denzin's "progressive-regressive" method of interpretation (Denzin 1989). This requires working both backwards and forwards from an event in order to understand what it represents to the narrator. The events that marked the limits of our time frame were Isabel's cancer episode and her amniocentesis diagnosis. The forward progression of our analysis began with the connection Isabel made between her fight against breast cancer and her decision to accept amniocentesis. She characterized both events as "God's tests" which were intended to allow her faith to grow. At the center of the progression was Isabel's account of her genetic counseling experience. This was when she was offered amniocentesis and faced the need to openly decide. We found this segment of her narrative provided the richest clues to understanding her behavior, since it was recounted with intense drama and in great detail, and referred to repeatedly during our many conversations. The progression ended when Isabel received a negative amniocentesis, indicating no anomalies had been detected in the fetus.

ISABEL'S BACKGROUND

Isabel was born in southern California and raised in a working class Mexican American community. When we met, she was living with her husband and three young children and was in her fifth pregnancy. She had reluctantly terminated her fourth on medical advice two years earlier. The family lived on the husband's intermittent earnings in construction, which rarely exceeded $20,000 a year. She herself had never completed high school and regretted the missed opportunity.

Although Isabel was 28 at the time of our interviews, she looked several years younger, despite the multiple hardships she had endured. In the previous four years she had been diagnosed with and successfully treated for breast cancer, had aborted her fourth pregnancy because her physicians feared it could trigger a cancer recurrence, and had endured ongoing marital problems and economic uncertainty. She blamed all this misfortune on a curse cast by a woman who, she believed, was set on destroying her marriage.

Isabel's closest relationships were with her children and with her father, in whom she felt boundless trust. He had converted from Catholicism to a very small Evangelical sect whose members were predominantly Latino several years beforehand and he remained very active in his church. He also persuaded Isabel to convert when she was diagnosed with cancer. She found her new faith comforting, especially during the difficult months of cancer treatment and emotional pain following her induced abortion. Following the teachings of her new religion, she vowed she would never end another pregnancy.

But two years later Isabel found herself pregnant again. The news was bittersweet. Although she desperately wanted another child, she was terrified that the pregnancy would cause her cancer to return. Yet she felt abortion was not an option. She was greatly relieved when her new physician minimized the medical risk of continuing the pregnancy and encouraged her to do so.

Isabel began prenatal care as soon as she learned she was pregnant. Without much reflection, like most U.S. women, she agreed to prenatal screening (Press and Browner 1997). As luck would have it, Isabel screened positive. While trying to decide whether or not to go for further testing to determine whether something was, in fact, wrong with the fetus, she happened to receive a phone call from a woman who was a fortuneteller.[8] The woman told Isabel her pregnancy was endangered by a curse cast by one of her husband's ex-lovers. Isabel concluded that she remained under the spell of the same curse which had caused so much misfortune in the past.

Around the same time, another event added more distress and confusion. A child with multiple, severe disabilities had been born to her neighbors across the street. Isabel told us she was terrified this could also be her fate and she went out of her way to avoid even setting eyes on her neighbors' child. In talking with us about this child with disabilities and the fears it evoked, Isabel's actual ambivalence about abortion became somewhat more clear. During our formal interviews, she repeatedly condemned its practice and swore she would never abort another pregnancy. Yet in speaking informally with us about her neighbors, she said that it might have been better for the family if the child had never been born (see Press et al. (1998) and Rapp (1998) for other examples of "doubled discourse" in women's narratives on disability and fetal diagnosis).

In deciding whether to seek genetic counseling and further testing, Isabel turned for guidance to her father and a few friends. They counseled her "to be confident, and to place [her] fears in God's hands." She said that "with a strong faith" and her sister's support she decided to attend the genetic consultation, but avoided informing anyone else that she would be doing so. She explained, "I didn't tell the others . . . I didn't want to worry them, especially my dad, I didn't want to let him down by not putting all my trust in God."

ISABEL'S AMNIOCENTESIS NARRATIVE

During our series of interviews, we asked Isabel to talk about what it meant for her to have screened positive and how she decided about amniocentesis. The following transcription is a condensation from the 4 face-to-face interviews and 2 of the 10 phone conversations.[9]

Most conversations were in English, although she typically switched to Spanish when discussing the curse and its effects. Spanish segments were translated by the second author. I refers to the interviewer and R to the respondent. Square brackets indicate where we omitted repetitious or extraneous material or added words for clarification; ellipses indicate pauses in the conversation.

December 11

I: How did you decide to go [for genetic counseling]?

R: They called me from my doctor and they told me that my . . . that the blood test they had taken was positive-low, that he wanted to see me; so I went. [text omitted] He told me that positive-low meant that maybe the baby could have Down syndrome . . . and I had to be there. [text omitted]

January 3

I: What do you mean you had to be there?
R: I had to be there because I had to go. They sent me a letter saying that I had to go for genetic counseling. . . .
I: And what happened?
R: I told them I was there for that test.
I: Did you go to have the test?
R: No, no . . . [I went] because my doctor told me they were going to explain all about the test. [text omitted]

January 15

I: Did you know that, if the test comes positive, one of the options is abortion?
R: Yes, but I didn't want to even think about that. They said I had to have counseling. I had to see a lady . . . I don't remember her name. But I remember her . . . she was staring at me with her brilliant eyes. Oh! . . . terrible, she was terrible.
I: Terrible?
R: She started telling me if I knew what Down syndrome was. I told her that not really; that I had an idea, that it meant mentally retarded. And she said, "Yes". She said, "Do you know how they look, the children that have Down syndrome?" I told her, "No". She started showing me pictures of babies that have Down syndrome . . . She caught me by surprise. I started getting nervous . . . like scared. She said that the only way to find out if my baby was like that, was . . . that I had to have that test. . . . And she looked at me . . . Oh boy! . . . she wanted to be sure that . . . that I understood that . . . that . . . I had to have that test.
I: Amniocentesis?
R: Yes. And she was telling me that . . . that . . . it was up to me . . . that if I wanted to have that test, it had risks: that the needle could poke the baby, or the water bag could break; or I could bleed. . . . I was already scared because she was telling me how the babies looked like . . . and then she is telling me the risks, and that made me more scared. Then, I told her, "No! I don't want to have the test." [text omitted] So then she told me, "Well . . . well it's okay," and she pretended she understood me . . . but she was looking at me with those eyes . . . How could you fight with her? So then she told me, "Well, wouldn't you like to know if your baby is going to be normal or if it is going to have Down syndrome? . . . Because if it does have Down syndrome, there's still time for you to have an abortion." [text omitted]
I: How did you feel when she told you that?
R: I wanted to cry. I told her, "No, I don't want to have an abortion, and I don't want to have the test." She . . . "Hmm," she said, "Well, it would be better to know." I told her, "You are telling me that it's my choice, but you're not . . . giving me a choice!" I didn't know what to do. I was just sitting there quietly for a couple of minutes. [text omitted]
I: And what happened [while you were quietly sitting there]?
R: A girl came and calmed me down.
I: A girl? A patient?
R: No, one of them [medical personnel]. [She said], "Have faith . . . Everything is going to be okay . . . you'll see . . . Pregnant women always worry, but the test always comes okay . . . and they feel better." She talked softly and calmed me down. So I told her, "Please help me."
I: And then?

R: I told her, “Just go ahead and do the test . . . Just go ahead and do it!” [text omitted]

January 17

I: And what would you say was the role, if any, of your faith or your religion in your final decision?
R: The Bible showed me to have faith, and to see the signals that God sends us.
I: Signals?
R: [Yes, last week] I was talking to this lady [who happened to call], And she goes, “I feel like you are pregnant” . . . I just freaked out . . . I’m like, I don’t know her, I never told her I’m pregnant. Then I start telling her, “Yes, but it’s a high risk,” and she’s telling me, “Well I’m not telling you to have an abortion, I’m against that but, you know, if you go to Church and you tell God that it’s the best for you, for your kids.” [text omitted]
I: And what was the sign you saw in that phone call?
R: That I didn’t need to be scared because He would be there for me . . . But, I was scared, I just said, “Bye, I have to leave,” and I hanged [*sic*] up, and I was crying and crying. I had done that [abortion] and I promised not to do it again . . . You have to realize that everything goes back when I got cancer . . . some woman made witchcraft so my husband and I would separate . . . and that’s when I got cancer. But I got rid of it. And I had the abortion . . . [And now], I got pregnant again and she said my baby was the one who received all the bad things because of the curse. . . .
I: So that was the sign?
R: That . . . talking to her made me strong . . . made me go to the Bible. God is telling me that with faith nothing is going to happen to this baby. So, like before . . . I knew He would help me. . . .
I: And what happened?
R: I went to the clinic and you know . . .
I: And then what happened?
R: Well, [when I came back] I was . . . very tired, confused, I felt very bad.
I: And what did you do?
R: I called my father.
I: Were you concerned about your family’s opinion?
R: Only my dad’s.
I: Why?
R: Because I’m sure my dad would prefer to pray [instead of having the amniocentesis done]. [text omitted]

March 1

I: And now that you have the test results, how do you feel?
R: Good, they already told me that everything is normal. [And] I feel happy because the baby is fine and my faith grew from what was happening to me now.
I: So now you have no more worries?
R: No . . . everything turned O.K. because I have faith in Him. [text omitted]

March 7

I: And . . . are you happy that you accepted the amniocentesis?
R: Well . . . what other thing could I have done? . . . Given the circumstances. [text omitted]

DISCUSSION

In analyzing Isabel's account, we discovered she had used a classic heroic style of narrativization (Propp 1971; Covington 1989). In it, the victim-heroine is initially overwhelmed by an unexpected and apparently uncontrollable event, which causes a major life disruption. As heroine, she vows to overcome the threat, though she must do so within the moral boundaries of her culture. As victim, she finds herself compelled to abandon her sheltered home and undertake a journey during which she encounters dangerous aggressors. Along the journey's course, she also meets allies who help her reach her goals. Ultimately, the heroine vanquishes her enemies and returns home enriched and transformed. We found this style reflected Isabel's narration of her experiences surrounding the positive screening test result and the threat it presented to her pregnancy: she situated her account within a larger life struggle, representing herself as an embattled "heroine" who bravely overcame obstacles, conquered opposition, and emerged victorious.

The narrative shows that Isabel's turmoil stemmed from finding herself in a 'no-win' situation. She felt she owed her life to the interventions of medical science, which several years earlier had cured her of breast cancer. Now, it seemed, amniocentesis was what the clinicians wanted. Yet the very offer of fetal diagnosis stirred up issues she had no wish to consider: the risks of an invasive medical procedure, the chance of a positive diagnosis, the possibility something grave could be wrong, and, if it were, the likelihood she would be offered an abortion. But within her protracted turmoil, one thing remained clear: Isabel wanted more than anything to do 'what was best for her baby.' But what did doing 'what was best' in fact entail? Depicting herself as a victim who had little choice but to agree to the test despite the strong negative connotations she and those close to her associated with it enabled her to make sense of her experiences and provide a rationale for her course of action (cf. Garro (1994) and Price (1987) on explicative models of sickness and suffering).

Isabel attributed the positive screening test result to forces beyond her control, specifically, the continuing effects of a curse cast years earlier by a competitor for her husband's affections. Depicting herself as a passive victim enabled Isabel to avoid, in her own mind at least, the censure she felt she would endure were those she was close to who were opposed to amniocentesis to know what she had decided.

Situations like Isabel's are faced each year by tens of thousands of U.S. women (California Dept. of Health Services 1998:1). And the distress she experienced was by no means unique (Rapp 1988, 1990; Rothman 1987). Yet while in some ways universal, Isabel's experiences with fetal diagnosis

were also shaped by the fact that she was raised in a working class Latino community and still lived in one. Latin culture appears to have influenced Isabel's reaction to fetal diagnosis in her view that her continuing misfortune was caused by a curse intended to rob her of her husband and in the importance she placed on her father's opinion and that of fellow members of her small Evangelical church (Finkler 1994; LeVine 1993).

Our intent in making these assertions is not to single out Latinos for the importance they may place in esoteric supernatural forces, or the value they attribute to close family ties; many non-Latinos are similar in both regards. However during our field work and interviews, we could not fail to notice that *trabajos* (works), that is, the manipulation of supernatural forces to break up a couple, were spontaneously evoked by at least 10% of study participants as explanations for the problems they were experiencing with their pregnancies, including screening AFP-positive. And in all but two cases, such explanations were evoked by recent immigrants. Significantly, as we already indicated, whenever Isabel mentioned threats to her marriage from *trabajos*, she switched from English to Spanish.

Nor is it our intention to claim that Isabel's concern with honoring her father's wishes derived solely from her Latino background, although the importance of filial loyalty in that population has been extensively described (Marín and Marín 1991; Sabogal et al. 1987). Moreover, the fact that her church was a small, mostly Latino congregation, led us to surmise that its values, which included a strong prohibition of abortion, contributed to her ambivalence about testing. Isabel's narrative, then, reveals a blending of cultural influences derived on the one hand from biomedicine, faith in Western doctors, and self determination and on the other from a Latino evangelical Christianity, a belief in *trabajos* capable of robbing women of their husbands, and the importance she placed in honoring family ties. Each appears to have significance as she recreated her course of action.

Yet at the same time, to overly exoticize Isabel's behavior and to attribute it too quickly to Latino "culture" is to miss a crucial point. Within the U.S. today, falling ill triggers a surge of information-seeking behavior (Chrisman 1977; Hunt et al. 1990), although the resources one draws on vary from group to group. Isabel, and others like her in this study, were no exception. They differed mainly in the sources of information they drew upon.

These working class Latinas were less likely than middle class European Americans to consult the continually widening range of informational resources such as libraries, self help books, data bases, hot lines, and the Internet. Instead, their information came largely from the cumulative

experience of family, friends, neighbors, and local lay experts whom they encountered at home, on the street, while shopping, in the laundromat, and on the telephone. As Frankel and his colleagues aptly observe, "... public perceptions of health risks are the outcome of a process termed 'lay epidemiology' ... in which individuals interpret health risks through the routine observation and discussion of cases of illness and death in personal networks and the public arena, as well as from formal and informal evidence arising from other sources, such as television and magazines" (Frankel et al. 1991:428). Such social and informational resources help create an ambience which steers women in a particular direction when they are ambivalent or uncertain about how to resolve a medical or other type of problem (Preloran and Browner 1997). What varies, then, by ethnicity (and by social class) is not that locally acquired lay epidemiological information influences women's decisions about health care for one group but not for others. The variance lies in the sources of that information and how they affect its interpretation.

CONCLUSIONS

This analysis of a narrative account of one woman's decision to undergo fetal diagnosis sheds light on the meanings pregnant women may attach to a prenatal test result. At the same time, it helps us to understand how culture and circumstance can interact to produce a particular outcome. We have tried to offer some clues as to why a Latino woman might end up "choosing" the same tests as her European American counterpart, but for different reasons. Hence, it is not only the power of "choice" which needs to be queried, but the contexts within which choices are culturally as well as individually constructed.

Our intent, then, has been to show that narrative analysis offers a valuable means to tease out the particular from the general, by illuminating the circumstances through which broader patterns come about. The longitudinal approach adds explanatory power. It provides a means for disentangling the differential effects of the diverse influences which impinge upon individuals when they engage in a specific behavior, such as making a medical decision. Lay advice may be invariate, but current life circumstances or prior experience sufficiently different for that same information to be appraised or acted upon in diverse manners. These results reiterate the importance of developing medical anthropological paradigms that take into account not simply interactions among macro and micro level processes but also the particular circumstances within which concrete

variables come together at the moment when a medical decision must be made.

Prenatal testing is offered on the principle that a woman's right to make informed decisions about her pregnancy entitles her to the information fetal testing provides. However, women do not universally welcome the choices prenatal diagnosis offers. Commentators such as Kolker and Burke (1994) suggest that the offer of prenatal diagnosis can confer on women "the burden of unwanted decision making" which includes taking responsibility for whatever one decides. Many women would choose not to be burdened with such a painful and uninvited decision with all the associated issues such a decision can entail.

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NOTES

1. Complications from amniocentesis are uncommon but include cramping, bleeding, infection, and occasionally fetal injury or miscarriage (Eiben et al. 1997; Marthin, Liedgren and Hammar 1997). Miscarriage rates following amniocentesis in California hospitals can range from 1/500 to 1/200 (authors' unpublished field notes, 1996).

2. The vast majority of women who screen 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 (Green 1994).
3. The California A.F.P. Program for Prenatal Screening is funded like an insurance pool. A single fee (as of 1995) of $115 is generally paid for by private insurance or MediCal, California's Medicaid program. It covers the costs of the blood screening test, and in addition, genetic counseling, ultrasonography, and amniocentesis at a State-approved Prenatal Diagnosis Center should a woman screen positive indicating the possibility of a fetal anomaly.
4. One of the study's objectives was to determine the role male partners played in Latinas' amniocentesis decisions. Of 991 potential participants, who were defined as women with Spanish surnames offered genetic counseling because they screened positive, 12.5% fit our two criteria: 1) at least one of the spouses had to have been born in Mexico or trace their families' roots to Mexico; 2) both spouses had to be willing to be interviewed. Of the remaining 876, 3% refused to participate, 32% were Latino but not of Mexican origin, 30% could not be reached by telephone, 26% were not offered amniocentesis, and 9% were interested but unable to participate for various reasons (e.g. family illness, planning to move out of the area, etc.). Selecting only women with male partners willing to submit to a lengthy interview may have biased the sample in favor of men who were more involved in family matters and in their wives' reproductive health care. However, our data show that women, not men, made most of the amniocentesis decisions. We therefore feel the effects of any bias in this direction are inconsequential to the results reported here.
5. $n < 147$ due to missing data.
6. This self-administered 12-question scale assesses the extent to which the respondent uses Spanish and English in everyday situations (e.g. reading, with friends, watching television). The minimum score of 12 represents monolingual use of Spanish and is scored 'least acculturated'; maximum of 60 reflects monolingual use of English and is scored 'most acculturated.'
7. All but two of the amniocenteses were negative. The two who tested positive both opted for abortion. In addition, the Level 2 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.
8. Approximately 10% of the women in our study said they had consulted with seers, fortunetellers, and/or *curanderos* in making their amniocentesis decisions. This figure probably underestimates the frequency of such consultations, for such behavior is quite stigmatized within Latino communities, both in Mexico and in the U.S.
9. December 11. This face-to-face interview was designed to elicit material about Isabel's motivation to attend the genetic consultation.

   January 3. After asking a series of questions from the semi-structured interview guide regarding socioeconomic background, we probed more deeply into Isabel's reasons for attending the genetic consultation, particularly what she meant in the previous interview when she said she "had to be there."

   January 15. Part of this interview focused on the issue of abortion in the context of Isabel's religious and philosophical beliefs. During this interview, Isabel's comment, "I didn't want to even think about it" led us to explore her fears. It was in this context that Isabel spontaneously linked the issue of abortion to her genetic counseling experience.

January 17. One objective was to examine the relationship between Isabel's religious beliefs and her decision to agree to amniocentesis. Again, Isabel herself linked these issues to her genetic counseling experience.

March 1. By telephone, Isabel confessed that she felt overwhelmed by "all the problems" she had had to handle in the previous months (e.g. her mother complained that Isabel was overly involved with her new religion; her family needed to move again, etc.). In this context, she again brought up the subject of genetic counseling and prenatal diagnosis and the fact that her faith in God had led events along a positive course.

March 7. The intent of this phone interview was to determine Isabel's degree of satisfaction with her amniocentesis decision.

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