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## Interrogating the dynamics between power, knowledge and pregnant bodies in amniocentesis decision making

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**Abstract** A common assumption is that women who decline prenatal testing distrust biomedicine and trust embodied/experiential knowledge sources, while women who accept testing trust biomedicine and distrust embodied/experiential sources. Another major assumption about prenatal testing utilisation is that women who are open to abortion will undergo prenatal testing while those who are opposed to abortion will decline testing. Yet, previous research has produced inconsistent findings as to what, if anything, distinguishes women who accept or decline the offer of prenatal diagnosis. Analysing interviews with 147 pregnant women, this paper questions these assumptions about the role of abortion views and pregnant women's relative trust in various knowledge sources on their decisions to accept or decline an amniocentesis offer after a positive result on an initial diagnostic screening. We found that pregnant women's attitudes toward different knowledge sources were equally, if not more, important factors than abortion views in affecting whether individual women accepted or declined amniocentesis. At the same time, our data reveal that the relationship between 'expert' and 'lay' knowledge sources is often complex and synergistic.

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**Keywords:** prenatal testing, pregnancy, medicalisation, experiential knowledge, biomedical knowledge

### Introduction

As recent scholars have noted, the prenatal period is increasingly defined as an appropriate subject for medical supervision in the US (Abel and Browner 1998, Armstrong 2003, Barker 1998, Browner and Press 1996, Georges and Mitchell 2000, Markens *et al.* 1997, McNeil and Litt 1992, Oaks 2001, Root and Browner 2001). Contributing to the medicalisation of pregnancy is the increasing 'normalisation' of prenatal fetal screening (Browner and Press 1995, Dolev 2007, Mitchell 2001, Taylor 2008). In 1986 California became the first state to mandate that all pregnant women who enrol in prenatal care prior to the 20th week of gestation be offered maternal serum alpha-fetoprotein screening (hereafter AFP) for neural tube defects, Down's syndrome, and other anomalies (Duster 1990).<sup>1</sup> Such blood screens are non-invasive procedures that pose no physical risk to the

woman or the fetus, the results of which can indicate whether the fetus is at 'high' or 'low' risk of being born with common birth anomalies such as Down's syndrome and Spina Bifida. Fast forward two decades to 2007 when the American College of Obstetrics and Gynecology (ACOG) published a practice bulletin that recommended that all pregnant women who enrol in prenatal care early enough be offered prenatal screening, regardless of maternal age. If a woman is found to have increased risk in an initial screen the ACOG practice bulletin recommends that she should be offered genetic counselling and further diagnostic testing (American College of Obstetrics and Gynecology 2007).

This trend toward reliance on various forms of biomedical knowledge – scientific, 'expert', technological, etc. – has led some to label such knowledge sources as having more power and 'authoritative' status, thereby eclipsing other knowledge sources, particularly what are referred to as 'embodied' and experiential knowledge sources (Davis-Floyd and Sargent 1997, Ehrenreich and English 1978, Jordan 1993 [1978], Martin 1987, Oakley 1984). However, other knowledge sources – embodied, experiential, community, familial, local or religious – have also been found to carry 'authority' in women's pregnancy decision making (Abel and Browner 1998, Beeson and Doksum 2001, Browner and Press 1996, Gammeltoft 2007, Ketler 2000, Lippman 1999, Markens *et al.* 1997, Martin 1987, Obermeyer 2000, Rapp 1999, Root and Browner 2001, Teman 2003), and pregnant women, like other patients throughout the world, are not necessarily fully 'compliant' with biomedical prescriptions. Instead, they are often reflective actors who critically consider medical advice, frequently using their own assessments of various knowledge sources to accept or decline physicians' advice. Furthermore, social statuses, identities and contexts, from gender and age to race/ethnicity and nationality, affect how the medicalisation of pregnancy is assessed and experienced by individuals, which is not always reflected in the simple measurement of whether or not pregnant women accept specific biomedical offerings (*e.g.* Atkin *et al.* 2008, Fox and Worts 1999, Ivry 2007, Ivry and Teman 2008, Lazarus 1994, Lippman 1999, Martin 1987, Mitchell and Georges 1997, Rapp 1999).

Given this context of and debates about women's experience of pregnancy in the contemporary US, we wondered what factors affect whether pregnant women accept or decline an amniocentesis offer after screening positive on an initial blood screen? Underlying much of the literature on medicalisation of pregnancy is the assumption that women who decline testing distrust biomedicine and instead trust experiential knowledge sources, while women who accept testing trust biomedicine and distrust experiential sources. Yet, previous research has produced inconsistent findings as to what, if anything, distinguishes women who accept or decline the offer of prenatal diagnosis. Some research finds social status differences and cultural identity such as religiosity, class, and race/ethnicity shape differently situated women's assessments of and choices about prenatal testing (Rapp 1999, Remennic 2006), while other studies find that there are more similarities than differences between women who come to different decisions about prenatal testing (Atkin *et al.* 2008, Garcia *et al.* 2008, Lippman 1999, Markens *et al.* 1999). In the context of the polarised nature of the abortion debate in the US, another major biomedical and media assumption about prenatal testing utilisation is that women who are open to abortion will undergo prenatal testing while those who are opposed to abortion will decline testing offers. The logic is that since there are no medical remedies for the conditions that are tested for prenatally, and in the case of amniocentesis there is a slight risk of miscarriage from the procedure itself, women who are opposed to abortion will not pursue prenatal testing. While some studies have found a relationship between willingness to terminate and test uptake (Atkin *et al.* 2008, Green *et al.* 2004, Kuppermann *et al.*

2006), other research suggests that abortion views do not cleanly map onto amniocentesis decision making (Farrant 1985, Garcia *et al.* 2008, Kelly 2009, Lippman 1999, Markens *et al.* 1999).

This paper further questions these assumptions about the role of abortion views and pregnant women's relative trust in various knowledge sources on their decisions to accept or decline an amniocentesis offer after a positive result on an initial diagnostic screening. We found that pregnant women's attitudes toward different knowledge sources were equally, if not more, 'predictive' factors than abortion views in affecting whether individual women accepted or declined amniocentesis. At the same time, our data reveal that the relationship between 'expert' and 'lay' knowledge sources is often complex and synergistic. Our findings suggest that categorising biomedical/expert and experiential/lay knowledge sources as discrete conceptual categories distorts how they often mutually constitute each other. Before turning to a more complete analysis of our data we first discuss the context in which this study was conducted, and the methods we used to examine these issues.

## Methods and background

This research was carried out in California where fetal diagnosis is offered within the context of their state-administered programme. Although diagnostic screening is not mandatory, approximately 67 to 70 per cent of women in the state who enrol in prenatal care are screened, with almost 400,000 partaking in the programme annually (California Department of Health Services 1998, State of California 2007). Although seven to 13 per cent of women screen positive on AFP only 0.1 to 0.2 per cent of all pregnancies result in the anomalies tested for (Cunningham 1998). This means that a not insignificant number of women receive an initial positive result on the AFP screen, results that can be nullified with further testing and/or the birth of a healthy baby.<sup>2</sup> Women who screen positive are referred for 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, they are not obliged to do so. However, only a small proportion of women who screen positive turn down the genetic consultation offer.

Study participants were recruited from seven California state-approved Prenatal Diagnosis Centers where amniocentesis is offered to women at high risk for bearing a child with a birth defect. All participants signed an institutionally approved informed consent form after being told about our study and asked to participate. Our study focused only on women offered amniocentesis because they screened positive on AFP – this is how our study participants obtained their 'high risk' status. As a result, these women's 'high risk' classification was for the most part something new and probably unexpected, and thus for most the prospect of amniocentesis was not necessarily anything they were considering when enrolling in prenatal care. Therefore, while our results may not necessarily be generalisable to all pregnant women, given the ACOG 2007 practice bulletin recommending diagnostic screening for all pregnant women we can expect more and more women to first confront the decision of whether or not to undergo amniocentesis in situations similar to the women we studied.

We conducted semi-structured, face-to-face interviews lasting one to several hours with 147 Mexican-origin women (see Table 1). We chose to interview this group because women from Mexican backgrounds were more likely than other groups to decline prenatal screening (Cunningham 1998). Additionally, since most research on reproduction more generally, and prenatal testing particularly, has focused on white, middle-class women we

Table 1 *Characteristics of Study Population\**

	<i>N</i>	%
<b>Country of childhood**</b>		
United States	45	30.6
Mexico	102	69.4
<b>Education</b>		
Primary or less	37	25.3
Secondary or less	72	49.3
More	37	25.3
<b>Household income</b>		
Less than \$10,000/yr	49	34.5
\$10,001 - \$20,000/yr	42	29.6
\$20,001/yr or more	39	27.4
Don't know	12	8.5
<b>Religion</b>		
Catholic	125	85.0
Other	15	10.2
None	7	4.8
<b>Amniocentesis decision</b>		
Decline	58	39.5
Accept	89	60.5

\*N is less than 147 for women when data are missing.

\*\*For sample recruitment, a US childhood was defined as being born in the US or having emigrated prior to completing primary school, and a Mexican childhood as having emigrated after completing primary school.

believe it is important to include, and focus on, women of diverse backgrounds and experiences in research studies. Of course, there is a question of whether this group of women is generalisable to the US population as a whole: we address what may be unique about this group of women in our discussion.

Interviews were conducted in the participants' language of choice (69% chose Spanish, 31% English) and usually took place in participants' homes unless they requested another venue.<sup>3</sup> All interviews were tape recorded and transcribed in the language of the interview. Answers to specific questions examined in this paper were translated into English by one of the authors (HMP) and a research assistant. Interviews were conducted after women had decided whether or not to have amniocentesis, and a small number were still awaiting their results. Interviews covered an array of topics about their current pregnancy. Given our interest in how women drew on various knowledge sources in their pregnancy more generally, and for the amniocentesis decision particularly, we focused on informants' responses that addressed their views on prenatal care and testing, their assessments of their current pregnancy, and views about their confidence in biomedical knowledge.

Our analysis was informed by grounded theory and inductive approaches to social inquiry in that rather than taking pre-existing abstract categories and applying them to the social world, concepts and theories were constructed from the data (Glaser and Straus 1967). After an initial reading of the interview transcripts, the first author created and applied coding categories in consultation with her co-authors. Therefore, the specific dynamics we identify are those that emerged as the data were analysed. In the following

analysis of the data we refer to women's accounts about trusting their body, their 'feelings', 'just knowing' and reference to friends' and families' pregnancy stories as embodied/experiential knowledge,<sup>4</sup> and women's accounts of listening to and trusting doctors, technology and science as biomedical knowledge, although in our discussion we then problematise these very conceptual categories.

## Findings

What, if anything, distinguished women in our study who accepted and declined the offer of amniocentesis? Except for country of birth, most common socio-economic variables such as education and income were *not* associated with these women's amniocentesis decision. Did abortion views affect their amniocentesis decision making? Yes and no. While a hypothetical willingness to abort did lead to higher test acceptance, those who said they would not abort under any circumstance were equally likely to accept as to decline the amniocentesis offer.<sup>5</sup> Did women's views on different knowledge sources affect their amniocentesis decision making? Once again yes, and no. Women who declined the procedure were generally more distrustful of biomedicine and trusting of experiential knowledge sources, while women who accepted were more trusting of biomedicine and distrusting of experiential knowledge sources. At the same time, we found that evaluations of and use of different knowledge sources were not always as straightforward as the initial patterns suggest.

In the following sections we first discuss those who declined the procedure before discussing those who accepted, the latter being the most common response in our data and elsewhere to the offer of amniocentesis after a positive diagnostic screen. Within each group we divide the women into those who say they would and those who say they would not abort a hypothetical pregnancy. This allows us to illustrate the ways that relative trust in *and* interactions between biomedical and other knowledge sources affected these women's amniocentesis decisions, while showing that their hypothetical willingness to abort remains, for the most part, in the background of their decision making. Overall, we find that those who accept and decline the procedure tend to have different perspectives towards biomedically and experientially based knowledge sources: at the same time, we also show that different knowledge sources are often drawn on by women as they consider what prenatal course of action is deemed necessary and useful for them when biomedically trained clinicians are telling them that their pregnancy is 'at risk'.

### *Unwilling to abort and declines amniocentesis: 'I'm not a doctor but I know how I feel'*

Women who said they were unwilling to abort under any circumstances and who declined the amniocentesis offer seem to be acting logically. Since they would not abort a pregnancy, and given the invasive nature of the procedure and its slight risk of miscarriage, these women are seemingly 'rational' actors. For instance, when reviewing reasons for her amniocentesis decision, Betsy<sup>6</sup> explained that no matter the condition she would not abort: 'Even if it comes out with one arm or whatever, I'm not going to have an abortion. I'm going to keep it'. On the surface, such women's abortion stance seems to be the driving force behind their refusal. Yet, a similar proportion of women who opposed abortion both accepted and declined the amniocentesis offer (49% vs. 51%), and of those women who said they would never consider abortion only 42 per cent said their 'pro-life' position was a major reason for their decision to decline the procedure. This suggests that such amniocentesis decliners' unwillingness to abort is only a partial explanation, if at all, for the

amniocentesis decision. Instead, we find that their decision to decline is shaped by their scepticism towards doctors and medical technologies and/or trust in their own experiential knowledge that the pregnancy is fine.

First, these women's amniocentesis refusal corresponds with their lack of complete faith in biomedical knowledge sources more generally. For instance, Betsy whose abortion position was clearly an important reason for her amniocentesis decision, responded to our question 'Should a pregnant woman do everything doctors advise?' by saying: 'No, they may be wrong too, you never know'. Similarly, Teresa's response to the same question reveals a view that doctors' knowledge can be challenged and questioned: 'I'll ask a million and one questions...I just won't go to what he (sic) says'.

In addition to not blindly going along with doctors' recommendations, many women in this group also said they trusted their own 'embodied' pregnancy experience which tells them that their fetus/baby<sup>7</sup> is fine. For example, Maria told us that she 'knows' her fetus/baby is fine because of the way she feels. When probed as to how she knew, she replied quite simply, 'the baby moves', a criterion, as we will see, that was used by many of the women to evaluate the health of the fetus/baby. Often trust in this form of 'embodied' knowledge – fetal movement – derived from experiences with previous pregnancies. This is illustrated in Mercedes's explanation as to how she knew her 'baby' was fine: 'My baby I felt it...moving since I was four months pregnant. A lot sooner than with my daughter and this one moves a lot'.

While knowledge sources that are experientially based are seen by these women as powerful and trustworthy, the relationship between different knowledge sources is also revealed in Christina's more general response to the question of whether a pregnant woman should do everything the doctor advises. Her account reveals how trust in experiential sources, combined with uncertainty about her doctor's knowledge, empowered her to confidently reject physicians' advice:

I'm in the process of switching doctors, she's a new doctor. My opinion is she probably just finished her residency. She was telling me don't eat too many potatoes because you've been gaining too much weight. And don't eat so much bread. She tells me that I'm going to have a hard labour. But, if I'm hungry, I'm going to eat. I'm not going to starve. I take what they tell me and I weigh it. What makes the most sense? I'm not a doctor but I know how I feel. If I'm hungry, I'm not going to sit there and think, I'm not going to eat because my doctor said I was going to eat so many meals a day.

What we see then is that this group of women turns down the procedure because they don't uncritically accept physicians' advice *and* at the same time because they 'feel' that their pregnancy is going fine. As a result amniocentesis is viewed as unnecessary.

At the same time, the rationale Christina provides for why she is switching doctors is that her current one 'probably just finished her residency'. By questioning her doctor's qualifications to advise her she is asserting the importance of both medical and clinical experience for 'expert' knowledge. This, in the end, is not a rejection of biomedical authority per se, but of a particular doctor who is just too green, in her view, to be a reliable knowledge source. Thus, on second look, we see that while many of these women's refusals are often shaped by a mistrust of biomedical personnel, they do not completely reject biomedicine. In particular, they often account for their refusal by drawing on medical authority and discourse. For instance, 19-year-old Irene's explanation for declining the amniocentesis offer was that although her risk for an affected baby was higher than what it

should be for a woman of her age, she still was at a low risk.<sup>8</sup> Maria, meanwhile, drew on medical authority more directly to account for her decision: after having an ultrasound she was told by medical personnel that she didn't need an amniocentesis.<sup>9</sup> As a result, like most women in this group, Irene and Maria saw their decisions to decline the amniocentesis offer as medically appropriate.

In the end, an unwillingness to abort is at most a partial explanation for these women's decisions to decline further prenatal testing. Indeed, the role of other factors, besides general views on abortion that impact on decision-making surrounding amniocentesis, becomes clearer when we examine the rationales provided by women who are hypothetically open to abortion yet decline the offer of amniocentesis after receiving a positive AFP result. The similarities between these women, and the group discussed above, reveals how perspectives towards biomedical and other knowledge sources are perhaps just as much if not more fundamental in shaping women's decisions about amniocentesis than their abortion views.

*Willing to abort and declines amniocentesis: 'While one feels fine, no one needs to be doing tests and more tests'*

What many of the women who declined the amniocentesis offer share is a distrust or lack of blind faith in doctors and medicine and more faith in experiential knowledge sources. For instance, Ramona who is hypothetically open to abortion does not see physicians as flawless. When asked if a pregnant woman should do everything her doctor tells her she responds: 'What is to guarantee the doctors know? They are human beings, and they make mistakes too....while pregnant you need to get as much advice from them [as possible], but also not to believe in everything'. Similarly, Clara's decision is also shaped by her view of doctors who she explained, 'are not 100 per cent either'. Not only does Clara view physicians as fallible she also feels 'nowadays more doctors exaggerate'. In the end, her mistrust and suspicions of medical personnel figure largely in why she doesn't see prenatal tests as necessary: '[I]t's too much...doctors who abuse...that one does not order a test and they test and test. Like now, during my pregnancy, they have done five tests. And I think at times it is just that they can charge the government, like MediCal does'.

Although not as extreme as Clara's distrust of the medical industry, some women's belief in physicians' fallibility seems to come from their direct knowledge of doctors' 'mistakes'. For instance, Pilar recounts other women's experiences with what seem to be false positives on the AFP screen:

[F]rom school, my teacher that was teaching parenting one of the secretary's friends said in church they were telling her that yeah, they took all these tests and they were saying that yeah her baby was going to come out Down Syndrome or something like that and everything came out fine but she just didn't take the amnio... and then some lady that I knew, that I know, her too ... her ex-husband's wife was going through the same thing and everything came out fine.

Pilar is clearly aware that doctors and their diagnostic procedures can be wrong. For this reason, even though she also told us that generally doctors do know more than patients and that one should follow their recommendations, she does not accede to all their recommendations.

In addition to questioning biomedicine, Pilar, like other women who decline amniocentesis, also has faith in experiential sources that tell her that the baby is fine. This comes from her feeling 'happy' and that she feels 'it's kicking, and it moves', signs to her

that the fetus/baby is 'normal'. Similarly, Clara who was clearly distrustful of medical institutions also drew on experiential knowledge to account for why she declined the amniocentesis offer. Like several other women who declined, she compares her current pregnancy to previous ones, and from the fetal movement she recently experienced she feels that her fetus/baby is fine. Thus, she explains, there is 'no reason for one to have prenatal tests...because while one feels fine, no one needs to be doing tests and more tests'. Once again we see that *both* faith in experiential sources and distrust of biomedical sources seem to shape women's decisions to decline the amniocentesis offer.

Simply to assume, however, that there is a strong distrust of biomedicine and faith in experiential sources among women who decline prenatal diagnosis mischaracterises these women's decision making and their complex relationship with medical authority. For instance, while Pilar talks about her happy feelings and fetal movement as assuring her of the fetus/baby's health, Pilar *also* feels that her fetus/baby is fine because of a biomedical source: an ultrasound indicates that her fetus/baby is small but fine, and she was told with no signs of Down's syndrome. In this case we see that biomedical sources bolster experiential sources. Additionally, although Pilar does express some wistfulness about not having the amniocentesis done, 'just to be confident about what's wrong with the baby', in the end she explains her refusal because she's 'scared of the needle' and "cause of the risks too, for the baby'. By referencing the risk of miscarriage from the procedure, Pilar is not rejecting biomedical knowledge sources, she is just willing to forgo them if their acquisition jeopardises her pregnancy. For those who decline the amniocentesis offer the decision to decline is thus accounted for as medically and maternally rational.

A close look at one woman's account of why she declined the amniocentesis offer provides a particularly interesting case, as her story highlights the various patterns and complex factors that come into play during the decision-making process. Monica, age 37, was born in Mexico and has had seven previous pregnancies, including two abortions. She is therefore not closed to the hypothetical option of abortion. However, her hypothetical willingness to abort is currently irrelevant as she states that she is unwilling to abort this particular pregnancy. What about her approach to different knowledge sources?

Monica, like many women who declined, utilises experiential knowledge sources to account for why she declined the amniocentesis offer. However, unlike some of the women discussed above it is *not* because she has faith in 'embodied' knowledge. As she explained, 'I think that if the baby is born unhealthy a person does not feel any symptoms'. Instead, her experiential knowledge derives from both her and her family's reproductive history in which all the babies in her family have been born healthy – this without anyone having had an amniocentesis. Additionally, her family members also recounted stories to her that the procedure was bad for the baby, that the needle from the amniocentesis was what caused problems in other people's children. As a result she is concerned that her fetus/baby is healthy, but that having the amniocentesis will cause the baby to be born unhealthy. Thus, different familial-experiential knowledge could have led her to undergo the procedure: 'If someone in my family had had the tests, and I would have seen that they baby was born healthy, then I would have said yes [to the tests]'.

As with other women who declined the amniocentesis offer Monica expresses distrust of medical institutions and personnel. Indeed, the racial motivations Monica proffers are particularly startling: 'Because look, in the hospital I have not seen American women. I have only seen Latina women and Black women, but no American women. Do they offer it to them also?...I think...why don't they offer it to the American women? That is what I think'. Monica's suspicions of why she was offered amniocentesis, formed in awareness of

the pervasiveness of racism in American society and the healthcare system, illuminate a reason why those from racial/ethnic minority groups may be more likely to turn down offerings of prenatal diagnosis.

Monica's case is striking not just because she is our only informant to raise concerns about racism in describing her amniocentesis decision-making process,<sup>10</sup> but that despite these concerns she expressed a complicated assessment of biomedical knowledge sources, sources that she does not reject outright. Indeed she generally supports prenatal tests and she thinks 'it's better to have them'. Why then did she decline the offer?

In her view, the amniocentesis was too risky. When asked if she thought the amniocentesis would be a good thing to get if there was no risk of endangering the child she replied: 'Yes, it's like the AIDS test, right? I think that all women should have it...everyone because it does not harm the baby... and one can know if you have it or not'. Thus, despite her earlier concerns about racism she did trust doctors.

QN: Then you do trust [the doctors]?

Monica: Yes! Now, if there are things that doctors cannot cure like this [from the amnio] then I trust, because the Lord cures too...but one cannot give all the work to the Lord.

QN: It's true. But in the case of the amnio, the doctors advised you to have it? Right?

Monica: Yes.

QN: And you didn't get it. Why?

Monica: Well, because there is no cure.

QN: Then you will listen when they offer a cure, but if not, then no?

Monica: Sure. If they told me 'If your baby is born unhealthy, we will treat it', then yes.

What we see then is that these women turn down the amniocentesis offer because they don't uncritically accept physicians' advice, but not necessarily because they reject biomedicine. Meanwhile, they may also feel they already have the knowledge that their pregnancy is fine, often from experiential knowledge sources. Additionally, while they may be open to aborting hypothetically, for some it is not an option for them at this time. All these factors may come into play during the decision-making process, the result being that amniocentesis is usually viewed as unnecessary. How do they compare with women who accepted amniocentesis testing?

*Unwilling to abort and agrees to amniocentesis: 'To know for sure one can't trust in anything...only the test'*

At first glance, women who are unwilling to abort and accept amniocentesis seem to be another contradictory case since there are few medical remedies for the fetal anomalies detected by amniocentesis. Since abortion sentiments cannot account for these amniocentesis acceptors' course of action, it is important to examine how similar information is sought and desired by all women regardless of the decision made. The difference between women who accepted and declined the amniocentesis offer often lies in how they draw on and evaluate different knowledge sources.

First, for those who accepted amniocentesis, but said they would not abort under any circumstances, their decision should be viewed in the context of their faith in doctors and medicine. For example, Laura is a strong advocate of prenatal care and testing and indicated that only doctors can tell whether the fetus/baby is healthy when asked whether

she thought it was necessary for a pregnant woman to undergo prenatal analysis, even if she felt fine:

Laura: I think as soon as she gets pregnant she should go to the doctor and get tests.

QN: Why should she enroll early in the pregnancy for prenatal analyses?

Laura: So they [the doctors] can check the baby and see how it is...cause otherwise, if you don't go to the doctor, you don't know if it's okay or not.

Similarly, Julia expressed belief in the 'expert' knowledge of physicians because of their training, as well as the ability of medical technology to provide wanted and reliable information:

QN: You said before that we have to do what the doctor says. Is that always?

Julia: In this, I think so.

QN: Why?

Julia: They have all these things now, like the ultrasound, where they can see with much more clarity what is inside.

QN: And with the amnio?

Julia: They know with that, they are doctors for a reason, they have studied, this is why they can tell us if the baby is fine or not.

In addition to trusting biomedical sources, women who accept amniocentesis often did not trust experiential sources. For instance, Anna feared that something could be wrong with the pregnancy although she was 'feeling' fine. Her views illustrate the sentiments of many women who accept amniocentesis who believe that experiential knowledge is not legitimate and trustworthy: 'One can't be sure only because one feels nothing [wrong]'. Other women in this group who agreed to the procedure similarly felt unable to determine whether their own experiences were 'normal'. Martha, for example, explained that this was her first pregnancy and as a result, she doesn't know what to expect: 'I don't have experience, this is my first pregnancy. I wondered what is wrong with this girl, she moves a lot! Now I realised that it is normal, but when one doesn't have experience, one has to follow what doctors say'. This case illustrates how the relative trust in biomedical and experiential knowledge sources, as they interact, influences some women's amniocentesis decisions. That is, lack of 'embodied'/experiential knowledge *combined* with trust in biomedical knowledge influenced Martha's acceptance of the procedure.

Besides trusting biomedicine and distrusting experiential sources, we also see that keeping open the option of abortion is not what motivates these women's acceptance of amniocentesis – they want the procedure for the information and reassurance they expect it will provide. This interplay between abortion views and different knowledge sources is illuminated in Tina's explanation of why information provided by prenatal diagnosis is useful – even if the results indicate a problem.

Tina: We decided to do it, but we didn't do it because we wanted to abort. No, not at all. I wanted to do it to be prepared. I didn't want to find out that day [of delivery]. I wanted to know before.

QN: And you had doubts, did you feel something was wrong with the pregnancy?

Tina: No because I have the experience with my other children. I had terrible discomfort with my other pregnancies and the babies were fine. To know for sure one can't trust in anything... least of all, how one feels, only the test.

QN: So you trust in tests and medicine?

Tina: Sure, this is why I come to the clinic, I believe they offer the best for me and the baby, and *I don't think they would be pleased if I didn't trust them* (emphasis ours).

Tina's last comment is revealing, as it alludes to a complicated dynamic between women's agency with regard to their faith in biomedical knowledge and their desire to be a good patient by not challenging their medical providers' advice.

We see in such accounts of amniocentesis acceptors that women often report a mistrust of experiential knowledge while simultaneously evincing faith in the 'expert' knowledge of doctors and/or medical technology. However, for some, it is sometimes experiential knowledge – the sense that something doesn't 'feel' quite right – that propels women to pursue medical techniques which can assuage their uncertainty. In other words, amniocentesis is sometimes used to alleviate women's uncertainty or confusion that derives from their 'embodied' experiences. It is not always because they mistrust or lack experiential knowledge, but because they seek to validate it.

As a result, it is important *not* to view biomedical and other knowledge sources as inherently in opposition – many women see various sources as powerful, valid and useful. In other words, accepting biomedical knowledge implies neither passivity in the face of technology nor a necessary distrust of experiential knowledge sources. Do these dynamics also play a role in the decision making of women who are willing to abort and accept the offer of amniocentesis, whose 'choices' on the surface, therefore, seem a bit more straightforward?

*Willing to abort and agrees to amniocentesis: 'I didn't go to medical school for 20 years, I don't know what should be happening with my body'*

As mentioned, in our study population willingness to consider the option of abortion was associated with a higher likelihood of amniocentesis acceptance. Seventy-five per cent of our informants who would consider abortion for themselves under some circumstances accepted the offer of amniocentesis. The relationship was even stronger for women who would consider abortion for themselves even if the circumstances were not 'extreme': 87.5 per cent of these women accepted the offer of amniocentesis. Of these women, a few like Carla were forthright in how the option of abortion figures in their assessment of prenatal testing:

Well, to me I think it's a good thing because the baby could come out deformed and I wouldn't find out until I gave birth and right now with amniocentesis they'll find out right away and there's still time for me to get an abortion done. So I rather have them do it to me now than wait later for the consequences I have to face.

Although not always as direct as Carla, it seems logical that this group of women's willingness to abort affected their decision to accept the amniocentesis offer. Yet, given our findings about the other groups of women in our study we believed that there was probably more to their amniocentesis accounts than their abortion views. In examining their views towards prenatal care we did indeed find, similar to women who were unwilling to abort and declined the amniocentesis, that a seemingly straightforward relationship between abortion views and the amniocentesis decision masks how these women's decisions are also shaped by their evaluation of various knowledge sources.

First, these women's decisions to accept the amniocentesis offer were often shaped by their lack of belief in experiential sources as it was for Manuela: 'You just hope that the baby is fine. But I don't think that I can feel it, like 'Oh, I know it's ok'. No, I don't believe that's possible'. Noelia's response to the question of whether she knows if the baby is fine also represents a lack of complete trust in one's experiential knowledge about pregnancy: 'Yes and no...one knows if it [the baby] is fine, healthy if it moves...if you gain weight regularly...but with that alone you don't know if the baby will be born with serious birth problems'. Not only does Noelia question how much her experience of pregnancy can tell her about the health of the fetus/baby she also explains how it's the expert knowledge of doctors that shape whatever experiential knowledge she has of the fetus/baby's health: '...it's not what I say...when you visit the doctor, the first thing the doctor asks is if the baby moves'.

Interestingly, several of these women did at times 'feel' that their fetus/baby was fine, but they could not brush aside their scepticism of whether such knowledge was reliable and trustworthy. For instance, in response to the question 'Some future mothers have told me that because of the way they feel, they know the baby is fine; do you think the same?' Nora responded: 'Anyone trained in the medical sciences would say that that's bunk...it's absolutely no reason to think that....If you ask me I'll tell you that mine is fine. That's what I think...or what I want to think...I might be completely wrong. I'll find out in a few days..'. This response is similar to Rita who thinks women merely 'brainwash' themselves to believe they have information that is only obtained via diagnostic tests.

To an extent like during those two weeks of waiting [for amnio results], I said, I can feel it, we are going to be fine. You know, the baby is going to be healthy. But only to a degree do you think like that.....I don't think that if you say to yourself, I'm fine, I'm fine, I'm fine. There could be something wrong, but you've already brainwashed yourself to say I'm fine, that you'd never be able to catch it.

Most of the women who accept amniocentesis do not trust their 'embodied' knowledge of the pregnancy. Yet, for a few it was precisely experiential knowledge that propelled them towards the amniocentesis. As Gabrielle told us, 'From the start I was saying that something was wrong. I felt it. Its little heart was beating fast. I knew something wrong (or bad) was coming, and that is the reason I had the test. I wanted to be sure'. In this case we see how use of biomedically based knowledge demonstrates an acknowledgment of and belief in experiential knowledge sources rather than part of the denigration of them.

For the most part, though, these amniocentesis acceptors did not trust experiential knowledge sources while claiming much more trust in the power of biomedical sources. For instance, both Vanessa and Betty, respectively, did not think they could tell by themselves if their fetus/baby was fine 'because how could I know if the baby came with more [chromosomes]' and 'because some problems are only detected by tests'. More importantly, amniocentesis acceptors trust the doctors who care for them. Their sentiments towards medical personnel are quite different from those who declined the procedure. An example of this confidence in physicians is Angela who declares, 'I trust doctors and have always listened to them'. Likewise, Denise responds to a question about whether you should listen to your doctor with a clear affirmative: 'Yes, she ought to listen to everything...the most important thing is to place yourself in the hands of your doctor...they will inform you, and if one pays attention...it is the safest'. Rita was also quite adamant that not only are doctors more knowledgeable than she, even about her own body, but they also can be trusted:

I agree with the doctor knowing more than you. I mean, I didn't go to medical school for 20 years. I don't know what should be happening with my body, so I'm going to take the doctor's advice and the doctor's opinion.... Of course I'm going to listen to them, they have taken me this far. They have no reason to say anything bad or to steer me in the wrong direction.

While these women show much trust in biomedical knowledge sources this does not mean that they were blindly compliant to all medical prescriptions. For instance, several women displayed a lack of complete reverence for doctors in general, but when it came to their own doctors their opinions changed. This complicated assessment of biomedical personnel is illustrated in Vanessa's answer to our question if you should do everything a doctor recommends: 'No, because they don't know it all. But my doctor is great'. Similarly, in response to this same question Helena explains how she carefully evaluates her physicians' recommendations, recommendations she usually listens to, but not first without doing her 'own research':

The way I see it, there are some doctors that are very conservative and some other ones are too liberal so the way I react to things...I take all the common and then I usually do my own research through books or asking other people that have experiences or what have you and then I make my decision from that. I don't totally rely on the doctor but I do take their advice into consideration because that's what they do for a living. But I agree....that nowadays, I think there is so much more out there, that they don't know it all. But definitely they have a... probably a better guess than we do.

Helena's reply shows that she does seek out the experiences of others and does her own research in evaluating physicians' recommendations. In doing so she is behaving as a medical consumer: someone who will seriously consider medical advice, but engages in her own research. These types of accounts illuminate the agency women exert in their decision to undertake prenatal diagnosis.

Yet, in the end, Helena does confess that, given how complicated and expansive medical knowledge has become, doctors are the ones most likely to have the most reliable knowledge. Meanwhile, Aida's comments perhaps reveal the darker side of medicalisation, where medical 'choices' become non-choices: '[Y]ou never know what's inside you, because if I never went to prenatal care, I would of never known that I *had to take the amnio test*, I would never known anything like that...(emphasis ours)'. Such accounts, along with others by amniocentesis acceptors, suggest that women may make their own 'choices' regarding prenatal diagnosis, but not always under circumstances of their own making.

Furthermore, in understanding how belief in various knowledge sources shape each other, a closer examination of interviews reveals that the distrust of experiential knowledge sources expressed by many of these women was the result of their experiences of having a positive result for the initial AFP blood screen. In Danielle's case even previous pregnancy experience could not trump her doubts about experiential knowledge sources in the face of screening positive with the AFP. For Rita, her positive AFP experience confirmed the importance of biomedical knowledge sources over experiential ones:

I felt fine before I took the AFP, I felt fine after I took the AFP. Just the normalcies of having the baby, of the stretching and the uncomfortableness and all that ness. And now they are finding out that I have high blood pressure, that there might be a

chance of the baby coming out with Down Syndrome. And as a mother I would want to know everything...So prenatal testing is very important.

## Discussion

As others have noted, the increasing emphasis on genetics in health care has led to expanded notions of 'risk' and to 'surveillance medicine'. The Human Genome Project, which the expansion of prenatal diagnosis is tied to, thus further drives (bio)medicalisation processes (Clarke *et al.* 2003, Conrad 2005). What do the experiences and accounts of women in our study tell us about the medicalisation of pregnancy and prenatal diagnosis' role in it?

Many of the amniocentesis acceptors do seem to understand that the offer of the amniocentesis after their AFP positive result carries some 'authoritative' power (Browner and Press 1996). For instance, several of the women who accepted told us that they didn't want to disappoint their physician by declining the procedure. Others said that amniocentesis must be worthwhile because it had been recommended by medical personnel. And in one case, a woman believed she 'had to' take the test after receiving a positive result on the AFP blood screen.

At the same time, one of the most common reasons women with no intentions of aborting a pregnancy will give for accepting prenatal screening is 'to be prepared' (see Press and Browner 1997). In part, this response is explained by the nurses, physicians and genetic counsellors who, in our observations, sometimes seek to encourage testing by saying the information will help avoid shock at birth and allow time to prepare family members. Providers additionally state that they can be prepared with specialists during the delivery and have time to look for any appropriate institutional support, in the event of a positive diagnosis (see Browner and Press 1995). These findings provide a powerful warning of how institutional processes can confer authoritative status and suggest the possibility of ever more medicalisation of pregnancy with the proliferation of biomedical techniques, even if procedures are 'optional' and there is seeming consumer 'demand' for it (Browner and Press 1996, Conrad 2005, Farrant 1985, Rothman 1984, 1986, Terry 1989, Vassy 2006, Williams *et al.* 2002).

Women's 'choices' of whether or not to avail themselves of prenatal diagnostic technologies must also be viewed vis-a-vis the gendered context of increasing expectations of intensive and exclusive mothering in which women are held individually accountable for their mothering/parenting and in which more and more is expected of women as mothers (Blum 1999, Hays 1996, Mitchell and Georges 1997, Remennic 2006, Schaffer *et al.* 2008). Childbirth has been labelled a 'rite of passage' to North American motherhood (Davis-Floyd 1992, Fox and Worts 1999), yet it seems that with the increasing normalisation of prenatal testing that the prenatal period has now extended back into the womb when maternal responsibilities begin and furthers the 'medicalisation of motherhood' (Green *et al.* 2004, Litt 2000). This is seen in our study when, for instance, an informant discusses her prenatal decision making 'as a mother'. As a result, women's decision making about prenatal diagnosis is the beginning of their ongoing activity of 'doing motherhood' in contemporary US society.

Why then were so many of our informants willing to reject these institutional messages and turn down the offer of further prenatal testing?<sup>11</sup> That many of these women drew on experiential knowledge sources, alongside their willingness to challenge medical advice, suggests that their ability to decline amniocentesis was shaped by alternate (*i.e.* less

medicalised) frameworks for understanding pregnancy. Whether such faith in experiential knowledge sources and distrust of biomedical sources is particular to our study population – women from an immigrant and ethnic minority background, the majority of whom were born outside the US – is an important question for future research. Will women of Mexican-origin background feel more or less pressure to present themselves as ‘modern women’ the longer they and their families have lived in the US? (Browner 2000, Mitchell and Georges 1997). Does this continuing faith in non-biomedical sources last with increasing time spent in the US, and as these women themselves experience and learn about the practices and power of biomedicine within the context of our highly medicalised health system and society? As more friends and families go through prenatal care (including prenatal testing) in the US, will Mexican-origin women rely less on experiential sources and more on medical ‘experts’ when making decisions about prenatal genetic diagnosis? At the same time, with more time in the US and experiences with its healthcare system women will have more first-hand knowledge – from themselves, friends, families and acquaintances – with the experience of false positives that are an aspect of the various prenatal screening techniques. The limits and possible inaccuracies of prenatal tests, and the anxiety such experience causes, may limit the extent to which Mexican-origin women, as well as other US women, uncritically embrace diagnostic technologies. This may prevent pregnancy from being fully medicalised the way in which childbirth has in the US, particularly for women who have alternative cultural resources to draw upon. Of note, Mexican-born women in our sample were much more likely than the US-born women to both believe that they can ‘tell’ if the baby is fine *and* to believe it’s important for pregnant women to do everything doctors advise.

Yet, given that we don’t have a comparative sample in this study, we should be very cautious about making any broad conclusions about assumed inter-ethnic differences with regard to the medicalisation of pregnancy. Additionally, the women who declined the amniocentesis offer in our study are not necessarily ‘resisting’ a further medicalised pregnancy or rejecting biomedicine. First, doctors gave them a choice as to whether to undergo the procedure and some were even told by medical personnel that it was unnecessary. Secondly, often biomedical notions of risk were used by women to provide a medical rationale for declining the amniocentesis offer (see also Markens *et al.* 1999). Meanwhile, the diversity of responses to prenatal care and testing within the Mexican-origin population we studied clearly points to intra-ethnic differences even among a seemingly homogenous cultural group. This is another reminder of the importance for clinical providers, and social scientists, not to stereotype and make suppositions about Latinas’ reproductive health decision making (Markens *et al.* 2003, Scrimshaw *et al.* 1997). For instance, our primarily Catholic study population had a very pragmatic view about the religion that permeates their culture and society. Thus, contrary to stereotypes, but not surprising given similar findings about women in Latin America (see Browner 2000), identifying as Catholic in and of itself was not a strong influence on amniocentesis decision making although some very adherent women will not abort for that reason (Browner *et al.* 1999, see also Atkin *et al.* 2008 regarding presumed religious differences among ethnic minority groups in the UK).

In sum, our analysis shows that neither women’s general attitudes toward abortion, experiential knowledge, nor biomedical knowledge map cleanly onto these Mexican-origin women’s amniocentesis decisions. First, women’s hypothetical willingness to abort does not have a straightforward and direct relationship to whether they accept or decline the offer of amniocentesis. Secondly, while women who declined tended to distrust biomedicine and have faith in experiential knowledge sources, they were also not fully ‘resisting’

medicalisation or solely putting their trust in their 'embodied' assessment of their pregnancies. Likewise, women who accepted tended to trust biomedicine and distrust experiential knowledge sources, but they also were not merely acquiescing to the 'authoritative' power of science and technology or rejecting experiential knowledge sources. In other words, our data reveal that medicalisation processes are not linear nor hegemonic. Neither were the women we studied 'cultural dopes'. None of these women were passive, even in the face of potent medical technologies. This is true, both for women who accepted and those who declined the amniocentesis offer. As such, scholarship on the medicalisation of pregnancy should recognise that the appearance of so-called medical hegemony over pregnancy, as measured by acceptance of medical technologies, is misleading as it may mask the multiple sources of information, medical and non-medical, that women draw on during the prenatal period – only some of which we have examined in this paper.

Our study thus contributes to feminist scholarship on the (bio)medicalisation of pregnancy that has demonstrated the unevenness of medicalisation processes, as well as women's own roles in furthering these processes. However, as feminist scholars of the medicalisation of pregnancy, we must be careful that in our attempts to recognise women's experiences not to romanticise 'lay' forms of knowledge as unaffected by biomedicine (Shaw 2002) and to recognise more explicitly how women come to embody medical knowledge.<sup>12</sup> For instance, in this study women's accounts of 'feeling' that their baby is fine because the 'baby moves' begs the question of how women come to 'know' this is a sign of a 'normal' and 'healthy' pregnancy – an observation made by one of our study participants. Unfortunately, our very use of certain conceptual categories may reproduce these misconceptualisations and the essentialisation of women's bodies. Ironically, in our attempts to reclaim and recognise women's experiences, and to demonstrate the ways that women challenge and utilise alternatives to biomedical knowledge, feminist scholarship on the medicalisation of pregnancy may, unintentionally, reaffirm a dichotomy between expert/biomedical and experiential/embodied knowledges that we seek to break down. Our objectives have been to challenge and move beyond these static dichotomies. In the end, our study suggests that knowledge and decision making in the prenatal arena is contingent, dynamic and synergistic, and that the (pregnant) body can be rendered both powerful and powerless in the face of advances in reproductive medicine.

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## Notes

- 1 In 1995 California added unconjugated estriol and human chorionic gonadotropin to AFP screening to improve the screening for Down's syndrome and trisomy 18 and renamed its program Expanded AFP-Screening or Triple Marker Screening. As of March 2009 California's Prenatal Screening Program will offer three types of screening tests to pregnant women: Quad Marker Screening (one blood test at 15-20 weeks), Serum Integrated Screening (combines first and second trimester blood test results), and Full Integrated Screening (combines nuchal translucency results with first and second trimester blood test results). California is still one of the only states with a state administered prenatal screening programme. See <http://www.cdph.ca.gov/programs/pns/Pages/default.aspx>, accessed on March 6, 2009).
- 2 Of the 147 women we recruited for our study, all but two of the women who had an amniocentesis had negative results. The two with positive results aborted. Two other women had level 2 ultrasounds that indicated anomalies. One of these women miscarried, the other gave birth to a baby with multiple anomalies.
- 3 See Preloran *et al.* 2001 for a further discussion of methods.
- 4 Research on the medicalisation of pregnancy utilises the term 'embodied' knowledge in diffuse ways. It tends to be a catch phrase for something on the bodily/physical/corporeal level from 'women's bodily knowledge' (Gerber 2002) to 'subjective knowledge derived from a women's perception of her body and its natural processes' (Browner and Press 1996). See also Mitchell and Georges (1997), Abel and Browner (1998), Lippman (1999) for other definitions, as well as Ivry (2007) and Ettore (2002) regarding related concepts.
- 5 We measured willingness to abort from responses to the hypothetical question 'Would you ever consider an abortion for yourself?' We coded their answers as 'no' (n = 76), 'in extreme circumstances' (n=47) and 'yes' (n=16). For the purpose of our analysis we separated the women into two groups regarding abortion views: those who said 'no' and everyone else. While a willingness to abort means different things for different women, especially for those who would only consider it under extreme circumstances (as these circumstances too vary), in the end there are only two options after a positive amniocentesis result: abort or not abort.
- 6 All names are pseudonyms.
- 7 We adopt the term 'fetus/baby' when referring to women's views of the entity growing inside them as we respect the ways in which women think of their child-to-be in a pregnancy they intend to carry to term. Adopting this language, we believe accurately captures the complex relationship between a pregnant woman and her yet-to-be, and often wanted, child.
- 8 Testing 'positive' on an AFP blood screen can indicate that a woman's 'risk' of having an affected baby is higher than it should be according to her age-level risk. Thus a woman in her teens and 20s may have a screening result that suggests that her odds are not very high for a Downs child, but her 'risk' level is higher than the average risk for women her age. At the same time, while different risk levels may therefore affect women's responses to amniocentesis offers, the meaning of the same risk level may also have different meanings for different women (see Rapp 1999).
- 9 If a woman screens positive on the MS-AFP for a neural tube defect but there is no obvious physical problem upon a follow-up ultrasound the AFP screening result is often assumed to be a false alarm.
- 10 Only one other informant brought up the possibility of racism, and she discounted these as other people's concerns. Whether this means concerns about racism are not salient for most of

our study population or whether this is an issue on which they remain silent cannot be determined.

- 11 This is not to imply that the only strategy of 'responsible parenting' is to choose prenatal diagnosis (see Kelly 2009). Similarly, women's decisions to undergo amniocentesis to 'be prepared', rather than abort, can be viewed as women possibly negotiating the seemingly contradictory terrain of responsible motherhood alongside community/cultural/religious pressure not to abort.
- 12 The vast literature that problematises the concept of embodiment persuasively demonstrates that 'embodied' knowledge must be recognised as socially derived knowledge in that it is developed through interactions with friends, family, media, as well as doctors and medical institutions. The scholarship on embodiment is clearly too vast to explore in depth in this paper.

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