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Genetic counseling gone awry: miscommunication between prenatal genetic service providers and Mexican-origin clients

C.H. Browner^{a,*}, H. Mabel Preloran^a, Maria Christina Casado^a,
Harold N. Bass^{b,c}, Ann P. Walker^d

^a Center for Culture and Health, Department of Psychiatry and Biobehavioral Sciences, University of California — Los Angeles, USA

^b Department of Pediatrics, Kaiser Permanente Medical Care Program of Southern California,
University of California — Los Angeles, USA

^c Medical Genetics, Kaiser Permanente Medical Care Program of Southern California, University of California — Los Angeles, USA

^d Department of Pediatrics, University of California-Irvine, USA

Abstract

Amniocentesis, and other prenatal genetic tests, have become a well-established feature of modern prenatal care. But these tests place a considerable decision-making burden on the expectant mothers to whom they are offered: the genetic issues involved are complex and the appropriate course of action sometimes ambiguous. Genetic counseling aims to help pregnant clients make an informed decision about prenatal genetic tests. But the clientele of prenatal genetic counseling has changed significantly in the years since the practice was established. Clients were once a self-selected group of women well-informed about the genetic services being offered. In contrast, clients now include an increasing number of women, particularly ethnic minority women, who had no prior knowledge of genetic testing, but were found to be at risk of birth defects after routine screening. Little is known about how well genetic counseling serves the needs of this new clientele. This paper investigates the possibility that miscommunication between genetic counselors and their Mexican-origin clients contributed to the higher rates of amniocentesis refusal. We interviewed 156 pregnant Mexican-origin women who screened positive on a blood test routinely offered in California to detect birth defects. We also observed the genetics consultations of a sub-sample of the women. We identified five common sources of miscommunication: (1) Medical jargon; (2) The non-directive nature of counseling; (3) The inhibitions of counselors stemming from misplaced cultural sensitivity; (4) Problems of translation; (5) Problems of trust. We found that many Mexican-origin women are skeptical of genetic testing and do not easily surrender their own lay theories about the causes of their condition. In order to dislodge the misunderstandings of their clients, counselors must give clients the opportunity to air their own views, however contrary to those of genetics professionals these may be.

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Introduction

Reproductive activities, from conception to child-birth, involve decisions that might have wonderful but also devastating consequences in people’s lives. In recent

years, the field of reproduction has grown in its potential for benefit and harm. Family planning, prenatal care, patients’ right to chose have become standard concepts in medical settings. But the benefits are not shared equally among different ethnic populations.

We are witnessing an “information explosion” in the field of genetics, an explosion fueled both by new discoveries (such as the mapping of the human genome) and by the wider implementation of older techniques (such as chromosome analysis and DNA testing). But the widespread availability of information does not

*Corresponding author. Department of Psychiatry and Biobehavioral Sciences, University of California, 760 Westwood Plaza, Rm. C8-699, 90024 1759 Los Angeles, CA, USA.
Fax: +1-310-825-9875.

E-mail address: browner@ucla.edu (C.H. Browner).

guarantee its widespread comprehension, and the new genetic information may not be well understood by the people whose lives it most affects. In particular, pregnant women are now offered a range of prenatal genetic tests for the diagnosis of developmental disorders and genetic abnormalities (Blatt, 1988). How well do they digest the complex and often ambiguous genetic data these tests provide?

Hospitals and clinics typically offer genetic counseling as a way to introduce prenatal genetic tests to women and to help them understand the implications of test results. Genetic counseling aims to be informative but “non-directive”, it seeks to help clients reach an “informed” decision, but refrains from steering or directing them. The goal of non-directive counseling fitted well with the expectations and needs of the counselors’ original clients, who were predominantly educated, middle-class women well-informed about obstetrics. Indeed, many of these women had sought out, on their own initiative, the genetic services they were being offered. But the clientele has since changed. Pregnant women are now screened on a routine basis to identify those at heightened risk of fetal abnormalities. This routine screening has widened the circle of women now offered genetic counseling. In particular, ethnic minority women today account for a significant proportion of the clientele of genetic counselors (Marfatia, Punaless-Morejon, & Rapp, 1990). Many of these women have limited formal education and no prior knowledge of prenatal genetic testing. It is not yet clear how well genetic counseling meets their very different needs (Marion et al., 1980; Marriott, Pelz, & Kunze, 1990).

How do ethnic minority women make decisions about fetal diagnosis, and why do refusal rates tend to be higher among African Americans, Latinos, and some Asian groups (Kuppermann, Gates, & Washington, 1996; Rapp, 1999)? A growing literature draws attention to some of the special issues raised by multicultural genetic counseling (Wang, 1998; Weil & Mittman, 1993; Myers, Echemendia, & Trimble, 1991; Rapp, 1998, 1999; Casas, Ponterotto, & Gutierrez, 1986; Carney & Kahn, 1984; Sue et al., 1982), but there has been limited observation-based research on the subject. The extent to which amniocentesis acceptance and refusal among women of ethnic minority backgrounds may be influenced by miscommunication between genetic services providers and their clients has not been well explored (Resta, 1999). In this study we focus specifically on the meaning of amniocentesis refusal among ethnic-minority women. By doing so, we do not mean to imply that there is anything problematic in refusing per se, but we thought it worthwhile to examine the relationship between miscommunication between genetic service providers and their ethnic-minority clients. Neither do we wish to argue that miscommunication is the primary

reason why those who did so ended up turning down the test. As we have discussed elsewhere (Browner & Preloran, 1999; Markens, Browner, & Press, 1999), there are other factors, such as the absence of male partners during counseling or patients’ assessments of risk, that were also strong predictors of test refusal. Below we will also consider instances of miscommunication where women agreed to amniocentesis. We argue that while miscommunication was not necessarily less common for the latter, the misinformation they took in appears not to have been sufficiently powerful to affect their decision to agree to be tested.

We focused on Latinos, because they represent a large and rapidly growing population in the United States, and they face a higher risk of neural tube defects (NTDs) than most other groups in this country (Stierman, 1995). NTDs result from failure of the embryonic neural tube to properly close at around 28 days after conception. The majority of NTDs affect the lower spine, in which case they are known as spina bifida or meningocele. NTDs of the skull, depending on their severity, result in either anencephaly or encephalocele. It is not understood why, but the California Genetic Disease Branch has reported that rate of NTDs among women living in Mexico is 5 per 1000, whereas the rates among first- and second-generation women of Mexican origin living in the United States drop to 2.5 per 1000 and 1 per 1000, respectively (G. Cunningham & S. Goldman, pers. comm., 2000). At the same time, Latinos use health services in general (Hunt, Valenzuela, & Pugh, 1998; Chavez, Hubbell, McMullin, Martinez, & Mishra, 1995), and amniocentesis in particular (Cunningham, 1998; Press & Browner, 1998), at a lower rate. There have been few studies of why Latinos are more likely to decline prenatal testing (Browner, Preloran, & Cox, 1999). This paper is intended to build on our understanding of why genetic counseling may go awry (Browner & Preloran, 2000) and to offer examples in which refusal may stem in part from miscommunication.

Background and methods

Since 1986, California has mandated that all women who begin prenatal care before their 20th week of pregnancy be offered maternal serum alpha-fetoprotein (MSAFP) screening as part of a state-run program, the Expanded AFP or XAFP program (Cunningham, 1998). Initially, only MSAFP levels were measured, but in 1995 screening was broadened to include two additional analytes: human chorionic gonadotropin (HCG) and unconjugated estriol (uE3). Higher-than-normal MSAFP levels are associated with open neural tube and abdominal wall defects, twin pregnancy, and certain other problems which can lead to obstetrical complications or fetal demise. Lower-than-normal levels of

MSAFP, in combination with specific HCG and uE3 profiles, are associated with Down syndrome (trisomy 21) and trisomy 18 (ACOG, 1996). Trisomies are conditions in which cells contain an extra chromosome. In trisomy 21 (Down syndrome), for example, there are three copies of chromosome 21 instead of two. From this “triple marker” screening it is possible to calculate a numerical risk for trisomy 21 and trisomy 18, but the screening is not diagnostic; women who screen positive are offered genetic counseling, ultrasound, and amniocentesis in an effort to establish a definitive diagnosis. They are also referred to a state-certified prenatal diagnosis center, where they are offered a consultation with a genetic counselor (trained to the master’s level) and additional testing (typically a high-resolution ultrasound and amniocentesis). These genetic consultations follow a fairly standard protocol, and typically include eliciting a family medical and genetic history, describing options for additional testing, the mathematical probability that the client would have a fetal anomaly based on the screening test result, and the risks of the amniocentesis procedure. It also includes discussion of the benefit of reassurance and preparedness, the right to accept or decline testing as well as the right to terminate the pregnancy if a chromosomal abnormality is found.

Our study population consisted of 120 women of Mexican-origin and their male partners, 27 Mexican-origin women who had separated from their partners while participating in the study, and an additional nine Latinas of working-class non-Mexican backgrounds, who have been included in this particular analysis because of their similarity of responses to the issues in question. All women had screened positive on triple-marker screening and were referred for genetic counseling and offered amniocentesis. In the present analysis, we focus primarily on the responses of women and not their partners. This is both because women’s explanations for why they turned down amniocentesis were more explicit, and also because, for the most part, men and women agreed that women’s decisions prevailed (Browner, 2001; Markens, Browner, & Preloran, 2000). Study participants were recruited from six southern California state-approved prenatal diagnosis centers to which they had been referred after a positive XAFP result.

The data for this article derive from the analysis of discourse between patients and genetic counselors as they discussed their prenatal genetic testing options, and our own face-to-face interviews with them (Frank, 2000; Frank et al., 2002; Garro, 1994; Mattingly & Garro, 1994; Riessman, 1993). In these semi-structured, open-ended interviews, the order of questions remained largely the same, but we followed up on topics that the respondents themselves raised. Where necessary, standardized follow-up questions were used to elicit further

information or clarification. The vast majority of the interviews were conducted after clients had decided whether or not to undergo amniocentesis. Interviews lasted an average of 1 h. Most were conducted in the interviewee’s home. For a few women—mostly single women or women whose male partners we expected to recruit later (see Preloran, Browner, & Lieber, 2001)—interviews were done at the recruitment sites themselves. Informed consent was obtained following protocols established in compliance with the university and each site’s institutional review board. If needed, supplemental and follow-up information was obtained by telephone. Interviews were conducted by one of the investigators (CHB or HMP) or by an interviewer who had been trained in ethnographic interview techniques (Bernard, 1995) and was bilingual in Spanish and English. We collated all the responses for each question in order to look for patterns across respondents (Patton, 1990). In addition, we drew on both scheme analysis (D’Andrade, 1991) and grounded theory (Glaser & Strauss, 1967) to explore the full narratives of individual clients, focusing on spontaneous explanations. Additional data come from systematic observations of 12 group prenatal education classes and 65 genetic counseling sessions with 10 different genetic counselors. Content analysis was used to discern patterns and trends in the observational data.

This part of our analysis was guided by two broad questions: What factors contributed to clients’ decisions to accept or decline testing? Were the reasons clients gave for their decisions framed by a genetic idiom? We hypothesized that in cases where there was lack of trust between client and counselor, born out of clients’ skepticism about the value of genetic testing, and lack of competent translation would distort communication to the extent that women would turn down the test. In categorizing women’s reasons for accepting or declining amniocentesis (e.g., one research participant who accepted said: “I wanted to be sure that my baby was fine.” One who refused explained, “I think I know how to manage [without the test]; I’ll take better care of myself [and] I can eat more protein.”), we began to establish provisional coding categories such as “Reassurance” and “Jargon-Protein.” Three project researchers read the interview transcripts and assigned codes to the relevant sections; consensus was achieved by analyzing the reasons for disagreement when they occurred. We concluded that four types of miscommunication accounted for the vast majority of the data: use of the word “protein” (we refer to this as “jargon”), the way (e.g., authoritative, neutral, etc.) that amniocentesis was offered (i.e. “prescription-suggestion”), clinicians’ failure to respond adequately to issues clients raised (i.e. “excess of cultural sensitivity”) and clients feelings that interpreters had failed to capture what they wanted them to convey (i.e. “translation”). In addition, the same

researchers read the transcripts of our observations of the clients' genetic consultation. This reading was done with four questions in mind, which were derived from the categories that came from the analysis of the interviews: (1) Do clinicians discuss the difference between fetal protein and source-of-energy protein? (2) How directive are clinicians when offering amniocentesis? (3) How do clinicians react when clients present beliefs that the clinicians feel are erroneous? (4) Do interpreters translate precisely what clinicians and patients say? After multiple readings of the transcripts, concordance was achieved with regard to the consistency between patients' explanations and ethnographer's observations. In searching for concordance, we asked ourselves, for instance, do counselors refer to protein or to fetal protein and if they do so, do they explain the difference? We found that most women who agreed to amniocentesis drew on clinical discourses such as the test's ability to provide reassurance or the opportunity it offered for preparation. Some also explained that they had been eating poorly, and they felt that as a consequence, their blood protein was low, but they wanted to have further tests to see if their condition had improved. On the other hand, as we will later show, that misunderstanding about protein, and other problems of communication, contributed to the reasons those who refused gave for declining.

We want to emphasize that by focusing on those who refuse amniocentesis we do not intend to imply that refusal is wrong. We also want to make clear the fact that the sources of misinformation we describe should not be considered *the* primary determinants of test refusal or evidence of counselors' malpractice. As Mattingly and Lawlor (2001) effectively show, patient-clinician communication is an inherently fragile endeavor. And although counselors may indeed genuinely wish to help patients make informed decisions, the biomedical culture, with its strong emphasis on clinicians' neutrality, may deter counselors from overtly challenging patients' views. One consequence is that counselors omit information in an effort to avoid seeming authoritarian.

Miscommunication and its consequences in prenatal genetic care

Thirty-eight percent of the study population declined amniocentesis. No socio-demographic variables were predictive. Both groups of women—those who accepted and those who refused—had similar reproductive histories (number of pregnancies, miscarriages, induced abortions, children who died, children with birth defects) and there was no difference in either family histories of hereditary factors or individual histories of reproductive abnormalities. In attempting to differenti-

ate the two groups, we also used Chi-square tests to examine any association based on a set of socio-demographic and attitudinal variables: e.g., age, education, access to economic resources, years in the US, religion, and feelings about abortion (see Table 1). Only feelings about abortion emerged significant as related to decision to accept amniocentesis ($\chi^2_{(2)} = 8.26, p < 0.05$). Only those few strictly opposed to abortion were more inclined to refuse the amniocentesis.

In the course of our research, we found a link between clients' explanations for their decision to accept or refuse amniocentesis and their understanding of what it meant to test positive on the triple-marker screen. Most of those who agreed to undergo amniocentesis attributed the positive results to chance, while those who declined attributed the screening result to a more concrete cause such as a transitory physical or mental condition (Browner & Preloran, 2000). The explanations given by those who accepted were usually a repetition of the medical information they received in genetic counseling. The reasons given by those who refused diverged more widely from this information. This led us to consider the possibility that miscommunication played a role in refusal. We hypothesized that clients who refused did not reject biomedical explanations out of hand, but their interpretation of the genetic information they received somehow moved them away from using the technology offered.

It was not a total surprise for us to find that client misunderstanding played a role in some women's decision to decline amniocentesis. Some genetic counselors had shared with us their concern that they were unable to convey their message to certain patients. Providers often blamed these gaps in communication on

Table 1
Background characteristics of study population

	Accepted amniocentesis <i>n</i> = 93	Declined amniocentesis <i>n</i> = 63
Mean age	28	27
Education		
[primary or less]	24%	24%
[secondary or less]	55%	48%
[more than secondary]	21%	28%
Household income		
< \$ 20,000 a year	69%	77%
> \$ 20,000 a year	31%	23%
Mean number of years in the United States for immigrants	12	10
Religion		
Catholic	88%	81%
Other (Evangelist, Jehovah's witness, etc.)	7%	16%
None	5%	3%

the low levels of education or the ethnic backgrounds of their clients.

At the same time, communication between prenatal genetic service providers and clients was found to be successful on many levels. Our observations confirmed that counselors almost invariably followed the standard protocol. They explained the advantages and disadvantages of the amniocentesis procedure and tried to make it clear that any decision (e.g., to accept or decline the test, to continue or terminate the pregnancy) would be the patient's. We also observed that most counselors talked sensitively about the often-difficult issue of abortion as well as other family related matters such as caring for a child born with a disability and religious, economic, and practical issues. Using [Roter and Hall's \(1992\)](#) model we found that "mutuality", in which the clinician provides expertise and shares the responsibility of medical decision making with patients, was the approach used by most of the counselors we observed.

Most clients came to the genetic consultation knowing that the measurement of certain substances resulted in an abnormal result (too high or too low), and that this was the reason they were referred for genetic counseling. But we also found that clients' interpretations of the meaning of a positive screening test often differed from the interpretations provided by the genetic counselor. To cast some light on the origins and characteristics of these misunderstandings, we have selected several cases that exemplify recurrent sources of miscommunication between counselor and client that we observed. We organize these cases under the headings "jargon", "prescription/suggestion", "excess of cultural sensitivity", "translation", and "trust".

Jargon

Health care providers, no less than other professionals, become fluent in a professional discourse heavy with technical jargon and specialized terminology. It is perhaps inevitable that clinicians sometimes lose sight of the fact that terms and usages familiar to them can have a different significance to laypersons and patients. Providers are also well-practiced in a jargon usually aimed at reassurance intended to manage the anxiety of patients undergoing testing. Effective communication can fail if clients misunderstand either the jargon or the reassurances that enter into the professional discourse of health care providers. These kinds of misunderstanding could sometimes be traced back to the information clients were given even before the triple-marker screening test. We will present excerpts from a 3-h Spanish prenatal education class given as part of the State of California Expanded AFP program. The instructor was an experienced nurse and very popular among the women who attended the class, in that they often sought her out to talk informally with her during breaks or

visited her office in search of advice. (We did not observe this kind of client-initiated informal interaction with the two other clinicians who participated in those prenatal education classes.)

In informal conversation, she told us she was especially concerned about the anxiety experienced by her prenatal clients and we observed that she appeared to make an extra effort to reassure them in class and privately that screening positive did not necessarily mean anything was wrong with the pregnancy. The expanded AFP classes introduce clients to the idea that they will be offered a screening test to help determine their level of pregnancy risk. In the class excerpted here, the instruction began with a review of the physiological and psychological factors women are advised to consider during pregnancy. Later, the health educator, in this case a nurse, briefly explained that she would offer a "standard" test designed to measure, among other things, a "protein" produced by the fetus that is present in the mother's blood. Normal amounts, she continued, indicated a "very good chance" that "the baby is healthy". In the middle of the class, the instructor reiterated that the blood test was "painless", reassuring, and risk-free. She said:

Knowing that everything is normal is a great relief, and don't be alarmed if your test comes out positive. We will call you if it's positive. You will be informed if your baby's protein came out high or low. That means that your baby has low or high protein compared with other babies that were born healthy. That is all. Do you know why your test could come out high? Well, because you may be carrying twins. [And] do you know why your test could come out low? Well, because perhaps you had calculated your dates wrong—that means your baby is younger than you thought.

Then the instructor informed her audience of their right to decline testing without jeopardizing their access to prenatal services. She also introduced the fact that the women would have to sign a form in which they either accepted or declined testing. After some discussion about when the results would be ready, the counselor reiterated the fact that they would have to sign the consent form. Later, another clinician came to talk to the women about physical and mental health care during pregnancy. At the end of the 3-h program the first instructor dismissed the class but not before repeating:

I see that most of you have signed the consent form for the test. Good! You will be called only if your test is positive. If we don't call you, don't worry... And if we call you, please, you don't have to worry, either. We may offer you other tests that are more complete or more accurate. Because, you know, this test [XAFP], the one that some of you are going to have today, doesn't say much. It's like a red flag that indicates 'be careful, pay attention.' So this is why

you might be offered other tests that will reassure you that everything is fine.

In this example, the educator did not distinguish between the fetal “protein” for which clients will be tested (a substance produced by the fetus throughout gestation, excreted into the fetal urine, and passed into the maternal circulation) and the popular meaning of protein (found in food to maintain energy). Drawing on this more conventional meaning of protein, many clients who refused amniocentesis attributed a “low” test result to weakness (Browner & Preloran, 2000). Similarly, the educator did not explain that the word “positive”, as in a “positive” test result, was an indication of possible fetal abnormalities. As we will see in the following examples, these misunderstandings combined with the repeated efforts to reassure clients that the test was “standard”, “painless”, and nothing to worry about, may have made the test result seem unimportant. Convinced that there was no need to worry, some clients saw no compelling reason to undergo the risks of amniocentesis.

Prescription/suggestion

In addition to misconstruing the reassurances of clinicians, it was not uncommon for the clients we interviewed to misconstrue the non-directive nature of genetic counseling. Accustomed to receiving prescriptive medical advice and carrying out “doctor’s orders”, these clients took the counselor’s reluctance to directly recommend an intervention as a sign that the intervention was not truly needed rather than what has become a standard part of prenatal care (Williams, Alderson, & Farsides, 2002; ACOG, 1996). For example, one participant, aged 24 and with no disabilities in her family, was living on a small income (less than \$20,000 a year for a family of four). She had first come to the US 6 years prior to the interview when she was 18 and pregnant by another partner. This was the participant’s third pregnancy. She had completed elementary school, worked as a baby-sitter and believed that she was going to have a healthy baby because “it moves happily like my first-born”. The following excerpt explores this client’s reasons for declining amniocentesis at the time it was offered.¹

Q: You decided on the spot [to decline amniocentesis].

¹In this and all of the following examples, square brackets contain words added for clarification; ellipses indicate pauses or the omission of repetitious or extraneous material, and an inclined line (/) indicates an interruption. We use C to denote the counselor, W for woman and M for man. When the researcher participates in the conversation, we use Q. The language used in the following examples was Spanish; English translations were by HMP.

A: Yes.

Q: Why didn’t you want to think it over?

A: Because I knew already, I didn’t want to do it.

Q: Mmm...you came knowing that you did not want it...?

A: Right, when they [from the XAFP program] called me and told me about the [amniocentesis] test; I told them I didn’t want to do it.

Q: What did they say?

A: That even if I didn’t want it, it’s always better to come/

Q: /Why?

R: For the [good of the] baby.

Q: What did they tell you?

A: The blood was a little low. I need to have an ultrasound and the test of the needle.²

Q: Your blood?

Q: They said the baby’s protein.

Q: Did they mention both tests: ultrasound and the test of the needle?

A: Yes.

Q: Did they explain something more?

A: They explained everything, but I don’t remember. I’m very forgetful.

Q: How did you feel when they called?

A: Okay. I thought—well, they told me that it could be low or high. I got low. It’s okay.

Q: You felt okay?... Really?

A: Yeah, because I thought I had less time of pregnancy [client believed she conceived later than she actually did].... When I had the blood test they told us that most of the time that is what happens.

Q: And why did you come here if you didn’t want the tests?

A: I wanted to have an ultrasound.

Q: Did you have it?

A: Yes.

Q: And what happened with the ultrasound?

A: It showed that I had my dates right.

Q: And what did you think? Why did the blood test come out low?

A: It could have been [low] because I haven’t been eating well. I don’t have any appetite. I already knew I wasn’t gaining enough weight.

Q: And what did the counselor say about that?

A: She didn’t pay much attention. I don’t remember those girls’ names [genetic counselor and translator]. Both spoke English. One was more or less blond, the other brunette, the brunette translated everything for me. Both were very nice. They didn’t say anything.

²“The test of the needle” is used by many Latina patients when referring to amniocentesis.

Q: Did you tell them this problem [the screening test was positive because you weren't eating well]?

A: Yes.

Q: And what did they say?

A: I should eat more.

Q: And about the amniocentesis?

A: It was better to have the amniocentesis, anyway.

Q: And why did you not pay attention to them?

A: They did not pressure me at all (*ellas no me obligaron para nada*). On the contrary, they told me not to be afraid and do whatever I wanted... They said [the offer of amniocentesis] was only a suggestion.

Q: Is that right?

A: Aha. [Besides] sometimes [the test] comes out positive and it doesn't mean anything.

Q: No?

A: No. This is what they said in the clinic [where prenatal screening was offered]. I don't remember how low the protein was...or they didn't tell me...but I believe it wasn't too low because the lady who called me [to refer to counseling] was very calm and here, they did not make a big deal of it (*no hicieron mucho escándalo*). They said: "I suggest you consider it but it is up to you to decide." They did not recommend it at all; it was only a suggestion. I'm sure I could catch up with my weight if I make an extra effort to eat for two.

We found that in our larger sample women, such as the one in this example, usually draw on two types of information when trying to make sense of the positive screening test result: the classes they attended at their prenatal classes as part of the XAFP program and the personal experience of friends and family (Browner & Preloran, 2000; Mittman, Cromblehome, Green, & Golbus, 1998). Both of these sources led some to decline testing. The medical setting, in its effort to be non-directive and highly reassuring, sometimes seemed to cross a line and its suggestions came to be perceived as only casual recommendations. In the home setting, the frequency of what some counselors referred to as "horror stories", which focused on the high-risk of harming the fetus, did not help in motivating test acceptance either. Drawing from these two sources, patients often concluded that in their own cases, amniocentesis was not sufficiently justified.

Excess of cultural sensitivity

Counselors in California, typically dealing with clients from diverse backgrounds, are aware that their counseling must be sensitive to the cultural background of the client, but there are occasions when a counselor's attempts at sensitivity can interfere with direct and open communication. Counselors are wary of address-

ing the mistaken beliefs of their clients when those misapprehensions appear to be rooted in the client's ethnic or cultural background. The following excerpts come from an observation of a genetic counseling session. This session was attended by a couple, whom we consider somewhat typical of our larger sample. Lidia³ was aged 24 and Rodrigo, her husband, was 25; they came to California together 3 years ago. Lidia had spent short periods of time in Los Angeles, living with her sister and brother-in-law when she was 16 and 20 years old. During her last visit, her brother-in-law arranged a job for Rodrigo, which enabled Lidia to return to Mexico to marry Rodrigo and return with him.

She was a homemaker and he worked in building construction; this was their second pregnancy. They had an uneventful family history, with the exception that the husband's brother seemed to have been diagnosed with spina bifida in Mexico. After counseling, the husband confessed to us that he was skeptical about the medical care in the US. For example, he said the counselor "didn't know how to explain his brother's recovery", and he had noticed that in Mexico there are fewer "mongoloid" and paralyzed children. He concluded that this situation comes about because "[US] doctors didn't seem to know how to treat pregnancies naturally".

The counselor addressed the offer of amniocentesis after an ultrasound ruled out misdating of the pregnancy. Prior to actually offering the test, the patient, her husband and the counselor had had a 35-min discussion that extensively covered the standard protocol. However, during this time, the counselor avoided discussing what she deemed to be her client's ethnic beliefs, because she feared she would jeopardize rapport with her clients. She later timidly suggested that they check the brother's diagnosis with his mother and even offered to talk to the Mexican doctor in an effort to further clarify the brother's diagnosis. (The couple did not take the counselor up on the offer.)

C: The ultrasound showed your dates are fine... The other thing to do is to see if there is any possibility of spina bifida... For that we have the amniocentesis test. [Addressing the man] You know about spina bifida because you said your brother had it.

M: My mother was told [that] but he came out fine.

C: Who told your mother?

M: A doctor, back home, in Mexico City. [The man explains that his mother worked as a maid in the home of a physician who gave her the diagnosis.] He said: "If your baby doesn't walk when he is 3, he won't walk, he will be paralyzed because he has a hole in the little dorsal spine."

W: That is...the problem in the dorsal spine...the spina bifida.

³All names are pseudonyms.

M: [The man explains that the doctor told his mother to take good care of herself] and she did take very good care of herself and my brother walked normally like you and me/

W: [to the counselor] /but you said there is no cure.

C: No, no cure. [She explains that the severity of the condition depends on the location of the spinal defect. The woman interrupted, saying]:

W: But, he is totally normal.

C. It could happen that the hole was very little and healed by itself. I don't know how that doctor made the diagnosis; it could have been a long time ago [the counselor seems to suggest that an older diagnosis can be less accurate.]

M: No, it was a few years ago, he is my baby brother.

The counselor did not seek to dispel the (mistaken) notion that spina bifida may be reversed during pregnancy if women take good care of themselves, and she did not elaborate on the increased risk associated with her client's family history and positive test result. When we subsequently asked the counselor to explain her reticence, she said that when clients bring contradictory "ethnic" data to a genetic consultation, she seeks a balance between "respect" for the clients' "cultural beliefs" and her professional objective as a counselor, which is to convey the fact that there may be a genetic or developmental explanation for the condition in question. This provider—and others like her—was somewhat uncomfortable directly challenging clients' cultural beliefs because they assumed this would offend their clients. In another case, for example, a client casually mentioned her concerns that the "bad result" of her blood test was caused by the mistress her husband had recently jilted. The counselor did not respond to the woman's concern, later telling us that the dynamic with their patients was not conducive to exploring that issue and firmly believed that talking about it would not affect her amniocentesis decision. On the other hand, as we will argue later, avoiding open discussion of those issues seemed to lead to a serious gap in communication.

Translation

When counselor and client do not share a common language and their communication must be through a translator, problems can occur not only because of the shortcomings of translation, but also because of group dynamics that may develop between counselor, client, and interpreter. In some cases, communication through translators not only hinders comprehension but can also inhibit the development of a trusting relationship between counselor and client.

The following field notes come from two sources. Part I came from a genetic counseling session conducted in

English with a bilingual English-Spanish translator, a secretary who had been called away from her usual duties. Part II comes from an interview with the same client, who we call Rosalia, soon after the genetic consultation ended. This client was both typical and atypical. Rosalia was typical in that she was aged 24 with no disabilities in her family; she had arrived in the US 3 years before the interview and had been suffering continued economic setbacks since arriving in the US. She attributed her positive screening test to a poor diet, economic problems, and the flu. She attended genetic consultation alone. At the same time, Rosalia was atypical in that she had married a man 20 years her senior and had completed high school in her native country (most of our population had completed only elementary school). She was also attending an English class, determined to learn the language, but, at the time of the interview, she spoke it rather poorly and needed to communicate through an interpreter.

Part I. The counselor, assisted by the translator, asks Rosalia questions about her family's medical history. The interpreter translates the questions in Spanish literally. No problems were reported on the client's father's side; she indicates, though, that her younger half-sister's (with her mother's second husband) legs were "semi-paralyzed" as a child. Learning this, the counselor probes to learn more about Rosalia's half-sister, but her questions, when translated literally, sound harsh and crude to the native speaker [*"estaba retardada?"*], and Rosalia appears discomfited. To each question about her sister's condition, she repeatedly answers that she is walking perfectly well now. (We learn later that the counselor suspected that the client's sister had genetic defects, but the counselor and the translator were also aware that the client did not want to discuss the issue further.) The counselor turns to the translator to discuss how the questions can be asked without upsetting the client. This discussion is not translated. In addition, throughout most of the consultation, the translator looks at the counselor, making eye contact with the client only a few times. At one point during the interaction, Rosalia repeats that her sister's condition has improved. It seems she wants to convince the counselor that this issue should not be of concern: "She is walking well now. She only has to use special shoes." The interpreter says only: "She said her sister is O.K. now." As we will discuss later, the client notices that her words were not faithfully translated, which confirms her sense that what she says is being disregarded.

During this genetic consultation we observed that the counselor explains to Rosalia that according to the ultrasound, the pregnancy is correctly dated and asks whether Rosalia would consider having an amniocentesis. Rosalia appears to remain doubtful. She says that she would "perhaps prefer to consider" having the test later on because she is not feeling all that well right now.

She explains that she recently had the flu and that she was not eating well when she had the triple marker screening.

The counselor challenges Rosalia, saying that “the flu” does not cause the test to come back positive. She urges Rosalia to decide as soon as possible because her pregnancy is very advanced. Rosalia does not answer. The counselor continues to describe the amniocentesis procedure, adding that the test allows the doctors to analyze the chromosomes for the presence of Down syndrome and spina bifida. She asks Rosalia if she remembers what they had discussed about these conditions. Rosalia shakes her head indicating that she does not. The counselor asks Rosalia if she wants to review the information again. Rosalia quickly says no. The counselor repeats that Rosalia can have the test today and avoid having to make a special trip back to the hospital. The patient responds: “If you want to do it because of my sister, she is well now. My mother says she was a little behind (*quedada*) when she went to school, but she is walking well now. She only has to use special shoes.” The interpreter translates this by saying: “She said her sister is O.K. now.” The counselor does not respond and instead changes the subject, suggesting that Rosalia use the phone in the office to call her husband to talk the situation over with him.

Part II. We explain to Rosalia that we would like to talk with her about the genetic consultation. She agrees. We ask if it was difficult for her to understand the information the counselor was trying to get across. She responds that it was hard for her to understand and then she changes the subject, adding that she disliked the way that the genetic counselor and the translator interacted with her: “They were talking to each other, not to me... I told her about my sister, she only needs special shoes. She didn’t say “shoes;” I think she didn’t say anything [about that].” Rosalia then insists that they were “very impolite” because they were talking to each other and excluding her from the interaction. She adds that she strongly prefers the service she receives at a community clinic close to her home where the medical personnel speak Spanish and are friendlier and less intimidating. Despite our best efforts to ascertain how well Rosalia felt the information about fetal diagnosis was conveyed, she repeatedly shifted the topic back to translation problems.

While, as Roter and Hall (1992) observe, power differentials render client–clinician relationships inherently problematic, these differentials are intensified when actors lack a common language. With this example, we wanted to demonstrate sources of miscommunication that go beyond simple errors in translating words. Skilled interpreting is a creative technique demanding the communication of ideas and concepts as well as the accurate translation of words. Listeners depend upon pauses, word emphasis, eye contact and a trusting attitude to understand the message. In this

example, those conditions were not fully met. On the one hand, the Spanish-speaking secretary was insensitive to the harsh connotations of a literal translation. On the other hand, she lost the trust of the patient when her translations were not faithful or comprehensive enough. Interpreters in prenatal settings usually offer no more than a somewhat literal translation of words. Often, bilingual individuals (those who attend the consultation with the client, administrative medical personnel or phone interpreters) were pressed into service without careful assessment of their competence. Other times, Spanish-speaking clients requested counseling in English, despite the difficulty they had understanding the language. The standard of translation, as we will argue later, is often inadequate for the delicate decision that clients have to make about the complex technological intervention they are being offered.

Trust

The relationship between counselor and counseled is a professional one, but it is not wholly impersonal. The degree to which a client can trust and feel comfortable with his or her counselor can have a bearing on the effectiveness of communication between them (Rapp, 1999). Anecdotal data from genetic counselors (S. Caldwell, pers. comm., 6 June 2000; M. Alvarado, pers. comm., 2 March 1999; Z. Tatsugawa, pers. comm., 10 July 1998) suggests that minorities in general, and Latinos in particular, may be highly skeptical of the motivation for offering the tests and the results that follow. They are unlikely to air that skepticism or engage in a full and frank discussion of the implications of the tests being offered unless they trust the counselor. But women from ethnic minorities may find it difficult to develop a trusting relationship with health-service providers of different cultural backgrounds, especially ones with whom they have had no prior relationship. The following excerpt might help to illustrate the struggles of one woman who is not sure where to place her trust. The narrative comes from an interview, which explored the client’s rationale for refusing amniocentesis at the time the offer was made. Rosa was 27 and living in the US for the past 2 years. The US, however, was not a completely unfamiliar environment. As a native of Tijuana, Mexico, she often visited the States with her first husband, and she worked in San Diego, California for a year in a “job exchange” program.

She attended genetic counseling with a friend. Her background was an unusual one in that she explained that she had been “touched by adversity”, but said that in relation to health, she and her family were all very fortunate. Expanding upon the “adversity”, she confessed she had been abused as a child, ran away from home, and was unable to complete elementary school.

When she was 22, she ended up in a relationship with a man who tried to kill her. At 24, she became pregnant but her child died at birth. When she decided “to cross the border” searching for a better life, she also wanted to be away from abusive relationships. One year later, she found a new partner in the US and again became pregnant. At the time we met her, her partner was under arrest and she was living with a friend who participated in the genetic counseling session and took care of her “out of charity”. This friend was instrumental in motivating the participant to seek prenatal care at a free clinic close to their home. From there Rosa was referred to the XAFP program, where she screened positive. She was offered additional testing. During our interview, we asked Rosa about what motivated her decision to decline amniocentesis.

Q: You said “no” [when the counselor asked the client if she wanted amniocentesis].

A: [No answer.]

Q You didn’t want to take your time to think things over?

A: I want to have this baby [because] it is the only family I have. She [counselor] wanted me to do the test of the needle. I don’t understand why. Do you know?

Q: I think it was the only way to make a diagnosis. In other words, to know if there was something wrong with the baby.

A: But at the clinic [free clinic] they told me that my baby was fine. In the other place [prenatal education class] they told me that the baby’s protein was low, but all other things were fine.

Q: I’m not sure about the [free] clinic you visited.

A: Maybe that doctor [in the free clinic] is not a real doctor. In Mexico free clinics don’t have real doctors. I don’t know about here. But he [in the free clinic] told me that I was fine and my baby was fine. He is very nice; he wouldn’t lie to me. Don’t you think so? Besides, that doctor helped my neighbor with her baby; she said I can trust him.

Q: I don’t know that doctor, but in the other clinic they might have told you that you could be offered more testing.... To know more about your baby.

A: Yeah, but not that the baby could be mongoloid; they never told me that.

Q: And here?

A: They said the baby could be mongoloid. That is what she said.

Q: How did she know? Did you have other tests?

A: No.

Q: Did you have only the blood test?

R: Only that/

Q: /and they said the baby could be mongoloid.

R: They said the baby had problems with the proteins.

Q: Oh, maybe the counselor said that there was a chance that the baby could be mongoloid.

R: But how could she [genetic counselor] know that the baby could be mongoloid because of that?

Q: Did you ask her?

A: No.

Q Why not?

A: She doesn’t listen to things. I told about the clinic and I told about my [financial] problems but she didn’t pay attention. [Besides] my neighbor is helping me now. I feel much better. I eat better. I told her [the counselor] that, but she didn’t believe me.

Q: How do you know?

A: It’s the way she looked at me. She said it doesn’t matter [about eating better and about the stress]. I told her I had problems but she said it’s nothing to do with the test.

Q: Oh.

A: Well, if she doesn’t believe me, I don’t believe her. [Besides] she didn’t check on me [the client expected a general check-up], she didn’t do anything; she only paid attention to that [prenatal screening] test. She was only talking about that test.

Q: Well, that counseling is about the blood test, they wanted to explain to you about that test and other tests.

A: I know, but in the [free] clinic each time I go they check on me and my baby. And in the hospital, too... they said the baby is fine; nobody there told me I needed to have the test of the needle.

Rosa felt that what she had to say about her diet and financial circumstances was not believed by the counselor. She then reciprocated this apparent lack of confidence: “Well, if she doesn’t believe me, I don’t believe her.” This example illustrates how many women with low levels of formal education attempt to reconcile different—and seemingly contradictory—sources of information. In this case, the client gives more credence to sources she feels she can trust, such as her neighbor’s doctor at the free clinic close to home, than to the suggestions of the genetic counselor, who failed to win that trust.

Genetic counseling misunderstood/genetic counseling goes awry

The traditional doctor–patient relationship is rapidly changing, especially in the field of genetic testing. The “doctor knows best” and the blindly trusting patient are no longer ideals. Instead the expectation lies in the development of partnerships aimed at allowing patients to make informed decisions. But acting as partners demands mutual knowledge and trust and solid communication that sometimes is difficult to achieve. Most

genetic counselors in our study were genuine advocates for their clients' views. Their counseling took into account their clients' values about abortion, their socioeconomic situation, their need for concrete medical explanations, and even their capacity to handle anxiety. Indeed, the counselor in our "excess of cultural sensitivity" example was, if anything, guilty of displaying too much deference to her clients' beliefs. She refrained from directly disputing the medical information her clients brought with them from Mexico. But the counselor's tactful reticence left the clients with the impression she did not fully understand the particulars of their case.

Yet most clients rated their genetic counseling experience very highly, even when an interpreter was required (Browner, Preloran, & Cox, 1999). The level of dissatisfaction expressed openly by one of our participants (the "translation" example) was almost an exception. However, even among women who were satisfied, we found some evidence of misunderstanding. These were most evident in two areas: women's assessments of risk and choice; and women's understanding of the nature of genetic conditions and the meaning of fetal "protein". As Lock (1998) observes, genetic testing often create new uncertainties and ambiguities. At the same time, however, we observed that some women in our study who refused genetic testing used the opportunity of the positive screening test result to forge their own strategies for dealing with the anxieties they felt. In the following discussion, we explore why these communication gaps arose and how patients reacted to them. Signs of miscommunication were evident in the way women assessed risk. Their fear of genetic abnormalities varied greatly depending on their perception of the genetic information they received. Most women, especially those who refused, received their first formal genetic instruction at prenatal classes, such as the one described in example 1, and information conveyed in those classes seems to have left an indelible imprint on clients' perceptions.

While women who accepted and those who turned down the amniocentesis recounted conversations they had had with family, friends, neighbors, and even clinicians as they sought to make sense of the new information they had been given about their pregnancies, each group used this information in its own way. Whereas those who declined said they heard from others that the risks were not worth the benefits, those who wanted the test said they had heard it could provide tremendous reassurance. Juanita, for example, who agreed to amniocentesis, understood that her positive screening test result was due to "imbalance". She explained, "When my test came back low my husband said it was because I hadn't been drinking enough milk and from that moment on I drank more. But at the same time, I wanted to be certain and the doctor said the only

way we would know for sure was by having the other test [amniocentesis]." On the other hand, those who refused, like the women in our example 2, recounted detailed "justifications" for declining derived from such factors as their misconceptions about the nature of alpha-feto protein and/or their beliefs that since the clinician had not pressured them to have amniocentesis that nothing could be terribly wrong with the pregnancy.

Prenatal instructors aim to inform women about the benefits and limitations of screening tests. They adopt a discourse of reassurance in an effort to keep anxiety at a minimum, but by doing so they can also contribute to misunderstandings. Instructors frequently repeated assurances such as, "This test [XAFP] is only a red flag; it doesn't mean too much." Those kinds of statements led some women who screened positive to believe that they were either at a very low risk or faced no risk at all. In their own minds, they assumed that prompt remedial actions—usually modification of diet and lifestyle aimed to minimize stress—would control or eliminate any risks indicated by the test.

For many women, this confidence was based on information that was only reinforced by the genetic counseling that followed the classes. Counseling suffered from the fact that patients attuned to a certain model of medical practice, expect a definitive diagnosis and definite prescriptions for treatment and cure. Patients do not know, or perhaps do not comprehend, that in the field of genetics, direct recommendations are best avoided. So when counselors avoid making suggestions or recommendations and remain neutral, miscommunication may occur.

As we have seen, one client (example 2) reported that her counselor had told her "not to be afraid and do whatever I wanted," in a sense "leaving it up to me". The client interpreted the lack of direct recommendations as a sign that the positive screen result was "not a big deal", since a real *peligro* [danger] would, clients presumed, call for a more dramatic intervention. Another participant whose XAFP-result was minimally abnormal, praised the counseling but declined amniocentesis. She said: "The girls (counselor and interpreter) were very, very nice. The one who came to translate for me was very sweet. She was only there with us for a few minutes, but she made me feel good. She told me not to worry; I guess if it was something really, really wrong she would tell me."

Even clients who attended the genetics consultation knowing that something was wrong—that certain substances for which they were tested did not match normal levels—were sometimes misled by the counselors' approach. When amniocentesis was not prescribed but only "suggested", many who declined assumed that their condition could be ameliorated without it (Browner & Preloran, 2000).

It should be noted that when a woman's screening test result indicated greater objective risk (e.g., an extremely

high AFP score or abnormal levels of more than one marker), counselors tended to spend more time with the client and to describe the significance of screening positive in more depth and detail. In this way, counselors conveyed their concern to clients, and communicated the seriousness of the risk and the value of considering further testing. Yet whether this made clients more willing to undergo further testing is not clear (Hunt, deVoogd, & Dygert, 2000).

As other authors have noted (Chapple, Campion, & May, 1997), we found that unfamiliar terms may conjure up distorted understandings of genetic information. Our evidence suggests that many of those who declined amniocentesis believed that physical or psychological conditions were responsible for their positive screening result. We have described how one client (example 5) expected a physical check-up to verify the accuracy of prenatal testing. Building on this misperception, clients speculated that they could take positive action to reduce the threat of genetic abnormalities. Clients who confused fetal “protein” with standard protein, as the word is commonly understood, were especially prone to believe that simple dietary changes could improve the low levels. This misinterpretation allowed women to feel more in control and made the risk [*peligro*] much less threatening. As we saw elsewhere (Browner & Preloran, 2000), a misinterpretation of positive screening results bolstered the optimism and eased the anxieties of some women who declined. These women expected to have healthy children because they were convinced they had taken appropriate remedial actions. This type of misunderstanding is not seen only in Mexican-origin women; researchers who work with other ethnic groups have reported similar findings (Cohen, Fine, & Pergament, 1998). Neither is it only manifest among women who refused. Some women who accepted amniocentesis also expressed doubts about the biomedical explanation that screening positive was a random event. These women usually looked for more concrete explanations for the test result and sometimes blamed such factors as their spouse’s alcohol or drug use for the threat of a genetic abnormality.

The fact that certain substances, such as “protein”, could reach abnormal levels during pregnancy was introduced to most study participants during a class about the XAFP program. As shown in our first example, some instructors discuss physical, psychological, and genetic information in the same prenatal class. This bundling of genetic and general health issues might lead women to believe these themes are in some way linked. Given this misunderstanding, the belief that fetal “protein” is affected by physical or psychological deficiencies seems eminently reasonable.

Finding ways to narrow communication gaps between genetic counselors and clients is always difficult in hectic

medical settings. It may be doubly difficult when counseling must negotiate cultural and linguistic barriers. In all face-to-face communication, a speaker’s words are accompanied by non-verbal clues, such as body language, intonations, emphasis, and pauses that clarify the speaker’s intended meaning (Scollon & Scollon, 1995). These clues are often lost in communication between people of different cultural backgrounds, especially when they do not share a common language and must rely upon an intermediary to translate (Banks, Ge, & Baker, 1991; Rapp, 1999). This kind of miscommunication is readily apparent in our “Translation” example above, but it exists as a sub-text in some of the other narratives we have presented.

Many of the women in this study entered their pregnancy with no plans for fetal diagnosis. For these women, the positive screening test result was both an uncomfortable and unexpected fact to absorb. Under these circumstances, misunderstanding the facts can have its consolations. It is comforting for clients to seize upon providers’ reassurances as evidence that their condition is not serious and further tests are not warranted. Likewise, clients may find it comforting to assume that when a counselor does not directly recommend any action then no action is necessary. We have seen that women suffer less anxiety if they believe (wrongly) that the causes of their condition lie within their control (Browner & Preloran, 2000). An alternative interpretation is that health providers’ concerns may not be shared by patients who fail to perceive the potential severity and untreatability of the risks and anomalies that are discussed (G. Jenkins, pers. comm., 10 October 2001). But regardless of interpretation, mistaking fetal protein for dietary protein is but one readily accessible route to the common misunderstanding that a genetic condition can have a controllable, in this case, physiological cause, such as a poor diet.

If misunderstanding has its consolations, genetic counselors face the difficult task of removing these misunderstandings and depriving clients of the consolations they provide. As we saw in the excess of cultural sensitivity example, while counselors may be aware that their clients may be emotionally invested in mistaken beliefs, they are sometimes reluctant to address such misunderstandings for fear of undermining trust and rapport. But this is to confuse the means with the end: rapport is an aid to open communication; one cannot sacrifice communication in order to maintain rapport.

In other cases, counselors were quick to point out to clients that their lay theories, preconceptions, or expectations were mistaken or irrelevant. But as we saw in the “trust” example, Mexican-origin clients, many with limited formal education and no prior knowledge of genetic testing, seem to not be predisposed

to accept the guidance of genetic counselors over and above the advice they receive from other, more familiar sources. Counselors find themselves in the difficult position of having to earn the right to have their counsel heard.

As our examples show, those clients who do not feel that their views have been listened to and respected, are less likely to listen to and respect the counselor's guidance. Miscommunication is often the result of asymmetric communication: the client is asked to accept what the counselor has to say, before the counselor has heard the client. In the "trust" example, the client complained that the counselor "doesn't listen to things"; in the "prescription/suggestion" example, the client mentioned that the counselor "didn't pay much attention"; in the "translation" example, the client complained that her translator disregarded what she had to say. These examples suggest that the best way for counselors to improve comprehension and win a hearing for their message is to give a better hearing to the words of their clients.

Conclusion

In analyzing the content and context of clinical communication between genetic counselors and pregnant Latina clients, we found predictable ways that these counseling encounters can "go awry". Among the ways this can occur is through inadequate translation and the use of jargon, as well as counselors' efforts to maintain neutrality (the edict of "non-directiveness") and their reluctance to directly contradict what counselors feel is the erroneous world view that clients bring to a genetic consultation. Cutting-edge diagnostic technologies, as much in the prenatal domain as elsewhere in medicine, have challenged the long established hierarchical relationship between patient and clinician. Patients are expected to become much more active in making medical decisions, despite the fact they may not necessarily wish to do so. Providers are required to share their knowledge and expertise with clients and they no longer have the final word in patient care. Free and open communication—as well as an awareness of the many opportunities for miscommunication—will be key to the success of this newly emerging medical paradigm. We have argued that understanding the sources and contexts of clinical miscommunication is important in and of itself, regardless of whether such miscommunication has a measurable effect on clients' medical decisions. Since "informed" consent is increasingly recognized as a basic right in medical care, such consent is best achieved when patients have a good understanding of the means and ends of the medical care they are being offered. This analysis is offered as a step toward achieving this goal.

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