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## Expectations, Emotions, and Medical Decision Making: A Case Study on the Use of Amniocentesis

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**Abstract** The medical decision-making literature has paid scant attention to how prior expectations of patients and clinicians can influence medical encounters and affect patients' choices whether to accept or reject medical testing or treatment. To illuminate the issue, we offer a reflexive analysis of the experiences of a Mexican-American couple offered amniocentesis based on the woman's age and prior pregnancy history. We examine the impact of three principal factors: incongruity between expectations and reality for both patient and clinicians; the actors' ethnic backgrounds; and the history and nature of relationship dynamics between the patient and her male partner. We conclude that unmet expectations on the part of both patient and clinicians evoked powerful emotions that altered the woman's previous intention to agree to amniocentesis.

**Key words** amniocentesis • emotions • Latinos • medical decisions • reproductive health

Researchers seeking to understand what factors shape patients' decisions about treatment and testing have, for the most part, focused on the patient's background including their social class, education and ethnicity (Nsiah-Jefferson, 1993; Rapp, 2000; Wang, 1998), as well as psychological variables such as locus of control (Coreil & Marshall, 1982; Grieshop, 1997; McGuigan, 1999). The effects on decision making of a patient's pre-visit expectations and/or actual clinical interactions have received very little

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attention. There is a similar dearth of information about the extent to which clinicians' expectations influence their own and their patients' clinical behavior. Rao, Weinberger, and Kroenke (2000) suggest that this is because we have few effective methods for eliciting either patients' or clinicians' pre-visit expectations, or charting their effects (see also Sanchez-Menegay & Stadler, 1994). In this article we show that the ethnographic method coupled with a 'reflexive' approach to the analysis of the resultant data can provide effective tools to analyze the relationships among patients' and clinicians' expectations, clinical communication and medical decision making. Knowing that patients do not always get what they expect from a medical encounter, we offer a case study of how unmet expectations on the part of both patients and clinicians evoked emotions so powerful that they challenged a decision about genetic testing that the woman had previously made.

Guided by theoretical work on emotions and behavior by Lawler and Thye (1999), our objective is to explore connections among expectations, emotions, and interaction in the context of medical decisions. Lawler and Thye posit that in types of social interaction they define as governed by the norms of 'social exchange,' self-interested actors (be they lovers, co-workers, patients and clinicians, etc.) depend on one another to achieve expectations and further, that unfulfilled or disappointed expectations produce powerful emotional responses (Averill, 1992; Clark, 1990; Hochschild, 1990; see also Damasio, 1994 and Lerner & Keltner, 2001, on the relationship between emotions and behavior). We suggest that unmet expectations and the emotions they produce can play a central – heretofore overlooked – role in patients' medical decisions (cf. Michie, Marteau, & Bobrow, 1997).

We focus on three successive encounters at a genetics clinic where a Mexican-American woman was offered amniocentesis and ascertain the impact of three factors: incongruity between expectations and reality for both patient and clinicians; the actors' ethnic backgrounds; and the history and nature of relationship dynamics between the patient and her male partner. This approach accords with the framework developed by Lazarus, who, in a seminal article, proposes that 'to get at the heart of the problematic relationship between the doctor and the patient [requires] . . . two areas of study: first, the social interaction between the doctor and the patient (rather than focusing on the patient); and second, the institutional level or intermediate level between the medical system and the doctor-patient relationship' (Lazarus, 1988, p. 47). Moreover, Lazarus argues, patients' interactions with health care providers are best understood if analyzed within the broader contexts of their life situations (Lazarus, 1988).

## METHODS

Our ethnographic data consist of systematic observations and interviews conducted following the standard anthropological conventions (Bernard, 2002) during a day of formal clinical encounters and informal interactions between the woman we call Rocio (all proper names are pseudonyms), her husband, several medical staff, and an ethnographer. Rocio is 1 of 156 women with whom we conducted semi-structured, open-ended, face-to-face interviews for a study of amniocentesis decisions by California couples of Mexican background (Browner, Preloran, & Cox, 1999).

Our study population was drawn from a mix of 11 public and private prenatal care practices and 11 California state-approved prenatal diagnosis centers (see Browner & Preloran, 1999 for methodological detail). All women in our study had been referred for genetic counseling because they had screened positive on alpha fetoprotein or triple marker prenatal screening. We also observed 145 prenatal genetic consultations and 39 sonograms and/or amniocentesis procedures. In addition, we interviewed an opportunistic sample of 50 Southern California prenatal genetic service providers including family physicians, obstetricians, nurses, genetic counselors, medical assistants and translators about their experiences providing prenatal genetic services to pregnant Latinas and other women. Because we wished to build a representative sample of pregnant women for our larger study, but also to seek opportunities for greater depth of data collection than a single interview would allow, we invited five women from this sample who expressed interest in longer term follow-up to participate in more intensive research.

Rocio was selected, in part, because the close relationship she established with one of us (HMP) upon first meeting gave us an unusual opportunity to observe her amniocentesis decision-making process in the making and her subsequent reactions during the 10 days she spent waiting for her test results (Balzano, Preloran, & Browner, 2002; Preloran, Balzano & Browner, 2003). This contrasts with other research on the subject, which typically relies on retrospective accounts (Ettorre, 1999, 2002; Green, 1990; Rapp, 1998; Rothman, 1998a, 1998b). In addition to a 2-hour formal interview, we conducted three face-to-face follow-up interviews and had 16 telephone conversations (11 initiated by us, 5 by Rocio) during the ensuing 2-month period. The strength of a case study approach such as the one offered here is that it provides a unique means to separate the particular from the general and illuminate the circumstances through which broader patterns come about (Levy & Hollan, 1998).

Content analysis, a standard technique for analyzing biomedical practices in institutional settings (Barret, 1996; Rhodes, 1991), was used to discern patterns and trends in the observational data (Bernard, 2002;

Denzin & Lincoln, 1994; Lantz & Booth, 1998). To conduct the content analysis, we abstracted information from our field notes in a standardized fashion (Taylor & Bogdan, 1998). A coding sheet was used to categorize moods and behavioral cues observed in clinicians and patients during the medical encounters. They included verbal and nonverbal signs that indicated, for example, friendly or conflictive emotions. We compared and contrasted these observational data with data from the interviews to discern reasons for such specific behaviors as Rocio's twice changing her mind about amniocentesis, and the clinicians' explanations of why they sometimes distanced themselves from interaction with her. To conduct the analysis, we followed the standard procedure requiring two members of the research team to read and independently score all of the data for each variable.

We used the grounded theory approach to the analysis of qualitative data (Glaser & Strauss, 1967) and the literature on inter-ethnic patient-clinician communication (Flores et al., 2003; Roter & Hall, 1992) to develop a preliminary hypothesis that the main conflicts that arose during the clinical encounter stemmed from cultural and linguistic barriers between the patient and clinicians. Employing the methods of reflexive anthropology to test our ideas (Behar, 1993; Behar & Gordon, 1995), we had three further contacts with Rocio about a year after her amniocentesis and met twice with the clinicians (except for the ultrasonographer, who had retired) after they read an early draft of this article. During these conversations with study participants, we found little support for our hypothesis regarding linguistic and cultural barriers. At the same time, the patient drew our attention to what she regarded to be more important: unmet pre-visit expectations and resultant emotions. Further scrutiny of our data focusing on these factors resulted in the analysis offered here.

To facilitate reading the following rather complex story, we have added footnotes where appropriate. The letter 'A' indicates information from interviews, and 'B' from observations. Numbers indicate who was present during the interaction (see Note 1 for key to codes). With the exception of one meeting between HMP and three clinicians in the reflexive phase of our analysis, all other interviews were between one ethnographer (CHB or HMP) and the interviewee, without others present.

## CONTEXT

In 1986, the State of California mandated the option of prenatal screening for all women who enroll in prenatal care prior to their twentieth week of pregnancy (Crandall, Robertson, Lebherz, King, & Schroth, 1983; Cunningham, 1998). Today, most babies born in California (and elsewhere

in the US) are screened for the most commonly occurring birth anomalies, including neural tube defects and certain chromosomal disorders (American College of Obstetrics and Gynecology, 1996). Californian women who screen positive are referred to a state-certified prenatal diagnosis center where they are offered a consultation with a certified genetic counselor and additional testing, typically high-resolution ultrasound, and if indicated, an amniocentesis. Genetic consultations typically follow a fairly standard protocol. This includes obtaining the woman's reproductive and family medical history, describing her options for additional testing, reporting the mathematical probability of a fetal anomaly based on the screening test result, and outlining the risks associated with the amniocentesis procedure. The consultation can also include a discussion of the benefits of reassurance and preparedness that fetal diagnostic testing can provide, the woman's right to accept or decline it, and her right to terminate the pregnancy if an anomaly is found.

### ACTORS AND THEIR EXPECTATIONS

Rocio, the focus of our analysis, is 45 when we meet, and the mother of four. A self-made woman, after a series of odd jobs, she became the owner of a small grocery. She has recently sold it and is thinking of opening another in her hometown in Mexico [B-10, B-22]. Alberto, 42, has accompanied Rocio to the genetics consultation [A-7]. He is her third husband and they have been together for 5 years [B-10]. Their relationship is not an easy one. She considers him a poor provider and feels he resents her family's many serious medical problems [B-22]. In fact, Alberto has not been able to find full-time work during the previous 2 years [B-24] and is currently laid off from his part-time job in a cardboard box factory [B-14]. Although this will be his first child, it is their second pregnancy together. Rocio aborted the first because she was not sure their union was strong enough, although she told him she had 'lost the baby'. Only recently Alberto learned through family about the abortion. [B-22, B-23, B-24].

A medical assistant who tells Rocio we are recruiting participants for a study, introduces us to her [A-1]. She is rare among the women in our sample in that almost immediately she explains that she has come to the clinic to have an amniocentesis for reassurance, but quickly adds that she is fearful about the procedure's risks and what problems the test might possibly find [A-8]. Most others in our study said they arrived at the genetics clinic without much understanding of why they had been referred (Browner, Preloran, & Cox, 1999). She mentions that she is excited by the prospect of being offered an ultrasound because it may reveal the fetus's sex, but more importantly, it will give Alberto a chance 'to see the baby.' Although she is apprehensive about the prospect of an amniocentesis, she hopes it will reassure her that everything is fine [A-8]. She indicates that she expects this, her first prenatal genetic consultation, to be similar to her

routine prenatal visits in her neighborhood clinic: friendly, fast, private, in Spanish, and confidential [B-22].

During her day at the genetics clinic, Rocio interacts primarily with four medical personnel: Maria, a Mexican-American medical assistant, Ana, a Mexican-American clerk, both in their late twenties [A-9, B-11, B-12], Kelly, a European-American certified genetics counselor in her thirties [B-13], and Bree, a European-American ultrasonographer in her sixties [B-27]. Maria and Ana come from similar working-class backgrounds, both personally experienced discrimination as children, and view their work as personal 'missions' to help improve the lives of Latinos in the US [B-25, B-28]. Neither has had any formal genetics training [B-11, B-12]. Maria's main responsibilities are patient scheduling, intake and translation, and Ana's are as a receptionist, although she is often called upon to translate if Maria is not available [B-11, B-12]. Both Kelly, the genetics counselor and Bree, the ultrasonographer, also come from working-class backgrounds, but unlike the other two, they primarily view their jobs as sources of income [B-26, B-27].

In subsequent interviews, we learned that Kelly and Maria anticipated no special problems with Rocio's genetic consultation [B-11, B-13]. In fact, when Maria had initially called to schedule the genetic consultation, she found Rocio talkative and open [B-25]. She reported that Rocio had volunteered that she was extremely pleased to have been referred to their clinic because she heard excellent things about the medical services there, enthusiastically adding that she was looking forward to having an amniocentesis because she was worried about a pregnancy at her age and wanted to know as soon as possible that everything was going well. Maria subsequently conveyed this information to Kelly [B-25].

The data derived from participant observations that follow show that for the most part, the participants' pre-consultation expectations go unfulfilled: Rocio reacts antagonistically, the medical personnel respond defensively, rapport is seriously compromised, and Rocio changes her mind about having the amniocentesis. The data come from three clinical encounters: Maria and Rocio's interactions during the clinical history-taking, Rocio and Alberto's consultation with Kelly, and interactions between Rocio, Alberto and Bree, with Ana acting as translator, during the ultrasound procedure. The time frame is five and a half hours. (Translations from Spanish are by HMP.)

## THE CLINICAL ENCOUNTERS

### *HISTORY-TAKING*

Rocio's first encounter is with Maria in her small, windowless private office, furnished simply with a desk and two chairs. She is unaccompanied because Alberto is still looking for parking. Maria introduces herself in Spanish and starts with general questions. Her head bowed, Rocio answers in

monosyllables or remains silent. Several minutes pass, Alberto is still absent and the women joke about men's difficulties coping with simple, everyday things like finding parking. Maria then says she wants to wait for Alberto before continuing. She adds that it's essential that she obtain a complete family medical history because many health problems 'tend to repeat themselves' and should there be something suspicious, genetic testing would be all the more important. Rocio suggests they continue without him. She adds that while the nurse at her neighborhood clinic reassured her that a genetics referral does not necessarily mean that anything is wrong with the pregnancy, the slight hint of a possible problem is making her 'crazy.' When Maria repeats that she wants to wait for Alberto before continuing, Rocio replies that they can continue without him. The conversation shifts to their shared maternal status and ethnicity. Maria explains that her parents lived in Mexico but came to the US more than 30 years ago. Rocio responds by stating that although she herself emigrated from Mexico just 6 years ago, 'I am already an American citizen.' Before she can finish her sentence, Maria says that she 'adores the land of [her] ancestors.' They seamlessly shift to the difficulties women today face balancing family and work, talking ardently about themselves for the next few minutes. Abruptly, Maria asks whether any of Rocio's relatives were born with disabilities. As Rocio begins to explain her older daughter's medical problems, Maria interrupts to ask the receptionist to look for Alberto. Hearing this, Rocio again tells Maria to continue without him so as not to 'waste time.'

When the women return to the clinical history, Rocio looks more attentive and makes frequent eye contact with Maria who asks whether this is her first pregnancy with Alberto. Rocio says no, it is their second, adding that she 'lost' the previous one. Maria asks no other questions about the circumstances of the pregnancy loss. Instead she shifts to the subject to Rocio's children's health. In a hushed tone, Rocio explains that although both her sons are healthy, her two daughters have serious problems: the older, who died when she was eight, was born with 'heart problems' which Rocio attributes to an iron-supplement injection administered by a pharmacist in Mexico, and the younger has 'schizophrenia,' although she is not '100% sick' [*no está cien por ciento enferma*]. A bit later, Rocio adds that although her brother's son never walked or talked, 'he has a good mind' and she attributes his disabilities to his mother having failed to cry out when she was in labor [*se aguantaba los dolores*]. Maria mechanically records Rocio's explanations for her family's medical problems without questioning them, but again interrupts to ask the receptionist to look for Alberto. Rocio waves her hand, as if to dismiss them from this task.

Finally finishing Rocio's family's medical history and with still no sign of Alberto, Maria starts asking Rocio about his family history. She says she doesn't know much but believes his family is 'a healthy one.' When Maria interrupts to say that they really must find Alberto because the genetic counselor is ready for them, Rocio replies that until she goes to have the ultrasound, there is no need as far as she is concerned. Then she adds that



although she has had ultrasounds before, 'This will be my first [amniocentesis].' Nodding, Maria offers to find an interpreter for Kelly, the genetic counselor, who speaks only English.

Left alone with the ethnographer, Rocio sighs uncomfortably and reveals concerns about her family's medical history that she omitted from telling Maria. She wonders aloud whether her daughter's schizophrenia could 'run in the family' because both her brother and one of her nieces also seem to have it, adding casually that talking about her daughter's schizophrenia in front of her husband makes her uncomfortable. Swiftly switching topics, she says that people she knows who have told her not to have an amniocentesis are just 'ignorant' and adds, 'I wanted to talk to you [the ethnographer] because my friends don't understand me.' Lowering her voice, she explains that in fact she had aborted the first pregnancy with Alberto and that she has hidden this from him. When Maria returns to say that Alberto 'seems to have disappeared,' Rocio replies that she is happy to have a few minutes to rest.

Maria again leaves and Rocio picks up her conversation with the ethnographer: What will she do if the amniocentesis is positive? Would she continue the pregnancy? She comes back to the subject of her daughter who died, and how difficult it had been to care for her. Angrily, she adds, 'This is why when [neighbors] say, "Don't have [the amniocentesis], you have to accept your child however it comes," I say, "Of course [I will accept it], but we also have to think how hard it is [to care for a child with disabilities]?"' Rocio looks very sad as she adds, 'My child didn't walk, she didn't talk and sometimes we were forced to leave her alone at home. When she died, it was like a relief.' She continues to reveal information she had not told Maria: 'When my child was born, the doctor said, "Your daughter is mongoloid; her tongue will hang out." Look! We love our children anyway, even when they are abnormal, we may even love them more. But it's also OK to think about that [abortion]. If they tell me that this baby is abnormal, I'll have to decide whether or not to continue [with the pregnancy]. These are things I need to talk about.' Throughout Rocio's extended monologue, the researcher offers words of sympathy ('It's so sad.' 'What bad luck.') and support ('Right.' 'Of course.').

### GENETIC CONSULTATION

This next setting is similar to the previous one, but the genetic counselor's office is a little larger and has windows. Also unlike Maria's, Kelly's office has books, informational brochures, and more comfortable chairs. To the extent that settings play a part in the transmission of messages, Kelly's office communicates a site for learning, a setting where important medical information is conveyed.

The interaction between Rocio and other actors who will play key roles in her amniocentesis decision remains our focus. Alberto has finally arrived, as have Kelly and Ana, the clerk who has been enlisted, on the spot, to

translate. Kelly introduces herself, adding that she understands a little Spanish. Speaking with a heavy accent, Alberto says he has no difficulties with English; Rocio remains silent. Obvious rapport quickly forms between Rocio and Ana speaking Spanish to one another and Kelly and Alberto speaking English.

After skimming the chart, Kelly starts asking about Rocio's family's medical problems. Her replies are monosyllabic and sometimes seem defensive; she bows her head from time to time, seeming to signal discomfort. She says that her younger daughter, affected by schizophrenia, was confined to a mental hospital the previous year, quickly adding that she herself does not consider her daughter's illness extreme. In response to a question about her nephew, she states that although he experienced 'growth problems, [he] is not a dwarf and has normal intelligence.' When Kelly speculates that Rocio's older daughter and her nephew might have had the same problem, Rocio seems offended. 'No,' she sharply replies, 'She was born big and sturdy [*rechoncha*] and got sick because of the vitamin injection.' Kelly seems skeptical, and says somewhat sharply, 'What kind of injection? Where did [it] come from? I think it would be better for you to have an amniocentesis because I'm just not sure about your daughter's illness. I don't have her medical records and I don't have your nephew's records. I can't know if they had something similar [her voice trails off]. It could be something genetic.'

Rocio frowns and puts her head down. After a few seconds, she repeats that she is sure it was the iron injection that caused her daughter's condition. Kelly does not immediately acknowledge Rocio's reply, and after a brief silence, turns to talk with Alberto about the new ultrasound machine. Enthusiastically she explains that the couple will be having 'the pleasure of christening it.' While Kelly and Alberto continue speaking animatedly in English about the technology and the importance of Rocio undergoing fetal diagnosis Ana reassures Rocio that the consultation is nearly over. Rocio replies that she is thirsty and hungry and Ana offers to bring her something from the cafeteria once they finish the consultation. Kelly casually asks Alberto whether there are any medical problems in his family. 'No!' he exclaims, 'Everyone is very, very fine, super fine, 100%. My little sister died when she was two but she was healthy. My father died when he chose to die.' 'Good, good. Congratulations!' Kelly replies. Her questions to Alberto about his family's health continue a few minutes longer, and Alberto explains that his sister died from pneumonia.

Rocio's head remains bowed, seeming to ignore Ana's translation of the conversation between Kelly and Alberto. Her rigid body posture shows she does not like what Alberto is saying. Kelly again urges the couple to think seriously about amniocentesis: 'You know that the ultrasound is not 100% accurate because if the baby for example has his little hand in a fist, one can't know if he has [all] his little fingers.' When Rocio shakes her head, as if to decline the offer, Alberto quickly intervenes, 'Of course it is better to have it [amniocentesis] – you wanted it, didn't you?' Rocio is silent. When Kelly asks, 'Any questions?' no one responds. She leaves to check on the

ultrasonographer. Ana also leaves, saying she needs to ask Maria whether she will still be needed to translate during the ultrasound procedure.

The couple remains alone with the ethnographer. Rocio seems anxious and depressed and pushes Alberto away when he tries to comfort her. He persists, 'They want you to think about the [amniocentesis] test. Didn't you say that you wanted it?' She responds, 'There'll be no need if the ultrasound comes out fine. And even if they tell me that the baby is abnormal, I'm not going to abort it.' Alberto tries again, 'This has nothing to do with [abortion]. It's only for knowing.' Alberto then leaves the room to add money to the parking meter.

The ethnographer tries to calm Rocio when she expresses frustration with the continuing long wait, unfavorably comparing this consultation with her experiences at her neighborhood clinic. The ethnographer takes this opportunity to ask Rocio whether she feels satisfied with the clinicians she has met so far today. Rocio takes a deep breath; a look of doubt crosses her face, but she quickly adds words of praise for Ana: 'she is gentle like the girls in my clinic, she gives me confidence' [*es simpática como las muchachas de mi clínica, que le dan confianza a una*]. Rocio also expresses satisfaction with the conversation she is having with the ethnographer, with whom she says it is 'easy to talk,' adding: not like the geneticist [as she refers to Kelly] who twists and questions each word' [*no como la genética que da vuelta y duda de cada palabra*]. Alberto returns as the ultrasound is about to begin.

## ULTRASOUND

This setting differs from the previous two, and again, to the extent that settings themselves convey information, here the message is that the patient will be treated. The room is cool and dark; its most prominent features are an array of medical equipment. Rocio lies on a narrow stretcher in the room's center. She is subdued and seems quite tired. Ana is still absent. Speaking in English to Alberto, Bree, the ultrasonographer, explains that the procedure usually takes about 15 minutes, and then remarks that the room is too dark for her to see the computer keyboard. Alberto offers to move the lamp. Bree asks Rocio, 'What was the date of your last menstrual period?' Alberto translates Rocio's reply, 'Five and a half months.' Quickly Bree objects, 'In this country we count by weeks.' After a short silence, Rocio asks for a blanket, but Bree interrupts her request, 'Don't talk! If you talk, it is impossible to register the image.' But soon Bree is again deep in conversation with Alberto about the new machine and invites him to view the movement of the fetus. Rocio seems to understand because she also moves to look at the monitor. She remarks that she is worried because she has not felt fetal movement, but her concern goes untranslated as Bree again asks for silence: 'I am measuring the heartbeats,' she explains. Ana enters with a blanket that she tucks around Rocio.

Throughout the rest of the ultrasound, the two camps remain stable: Alberto speaking English with Bree, mostly about technical features of the

ultrasound equipment, and Ana translating for Rocio and showing emotional support by smiling, touching her hands and offering words of reassurance. A radiologist arrives to tell the couple that the ultrasound is inconclusive and suggests they return to the genetic counselor's office to discuss other testing.

Once there, Rocio speaks up, 'I'm afraid [amniocentesis] would be very painful.' Kelly quickly dismisses her concern, 'It is like getting an injection. It doesn't harm the baby and the doctor who performs it has a lot of experience. He has been doing it for more than 20 years.' Alberto turns to Rocio, repeating what Kelly just said: 'Here they have people that are very experienced. This doctor is an expert.' Rocio still seems doubtful, 'And if something happens' Kelly adds, 'The possibility [of risks] are very, very low. Here [at this facility] they're only one in 500.' And [going back to Rocio's concerns about pain] 'we don't use anesthesia because it would be more painful than the actual amniocentesis.' Rocio still seems doubtful. Alberto grows more insistent: 'If you want to do it, you should decide right now!' Kelly concurs, saying that the pregnancy is very advanced. But instead of responding to Kelly, Rocio asks Ana, 'But if the ultrasound shows that everything is fine, why do I have to do it [the amniocentesis]?' Kelly seems to understand and replies that ultrasounds are often inconclusive, that's why amniocentesis is needed. Rocio interrupts, 'I can't do it! Because I saw in the video [shown after the history taking] that afterwards, one has to be careful for at least three days and I am raising a girl [her granddaughter] who weighs 30 pounds and I have to carry her.' Kelly and Alberto each suggest strategies to overcome her concern, but Rocio shakes her head no.

Ana, who up to this point, has simply been translating for Kelly, now begins talking directly to Rocio: 'This doctor is very good. He has 20 years of experience. I had my amniocentesis here and he did it. I was afraid like you – but [after it was over] I was very reassured and I had a son [and] he is beautiful.' The two women continue talking softly, their conversation interspersed with periods of silence. Ana takes Rocio's hand in hers. Looking exhausted, Rocio says she'd prefer to wait for another day. 'Fine,' Ana replies, 'You would prefer to come back. When? Tomorrow, the day after tomorrow?' When Rocio responds, 'But he wants me to do it today.' Ana replies, 'And what do you want? Because you are my patient, not him.' After a bit more silence, Kelly bluntly asks Rocio whether or not she wants the test. 'Yes,' she softly replies.

### EXPECTATIONS AND EMOTIONS IN THE CONTEXT OF A MEDICAL DECISION: A REFLEXIVE ACCOUNT

Our reflexive approach led to a dialogue with Rocio a year later in which we asked whether difficulties communicating with Kelly through a translator might have caused her to change her mind about amniocentesis. Rocio was emphatic in her denial: 'Of course I prefer Spanish, like at my

[neighborhood] clinic everybody speaks Spanish and there is no problem, one can talk to people in confidence, but with her [the translator at the genetics clinic] it was OK.' In fact, Rocio frequently praised Ana, the translator, for her empathy, even casually mentioning that it may have been the 'little push' [*empujoncito*] from Ana which gave her the courage to actually agree to the amniocentesis. Instead she attributed her indecisiveness to the different feelings she experienced during the genetic consultation and linked those emotions to the fact that the consultation had not gone as she had thought it would. We found she was frustrated by how long the consultations were taking ('It took forever . . . In my [neighborhood] clinic it is much quicker, even when I have to have my tests'). She also missed the camaraderie and the feelings of protected privacy there ('There it is better because one can talk in confidence, being alone among women'). These last two remarks focused our attention on possible links we had missed in our own analysis of the interviews and observational data between Rocio's expectations for the genetic consultation and emotions.

Rocio continued to focus on unmet expectations and feelings throughout subsequent probing about her reasons for changing her mind. She explained that she never expected her own account of her medical history to be questioned and also was unpleasantly surprised about how much interest Kelly took in Alberto's family history. In particular, Kelly's insistence on trying to pinpoint her older daughter's precise diagnosis in front of her husband made her so anxious she wanted to flee the scene; she feared disclosing prior Down's syndrome in her family would exacerbate pre-existing marital problems caused by Alberto's frequent invidious comparisons of his healthy family with her own. This expectation of limited disclosure was mentioned so often in Rocio's discourse that we came to regard it as a prime ordinate expectation.

Debriefing conversations with the clinicians two days after Rocio's genetic consultation and again one a week later gave us a chance to determine whether their expectations for Rocio's genetic consultation and perceptions of the kind of patient she would be, influenced their interactions with her. All the clinicians said they expected an easy and accessible patient because Rocio had been very talkative and indicated from the outset that she wanted an amniocentesis for reassurance. Maria explained that she therefore found herself caught off guard when Rocio seemed uncomfortable during the history taking, bowing her head and keeping silent, but attributed it to the fact that Rocio had had an especially long wait for her intake appointment. She justified disappearing from the scene during the ultrasound by saying she felt that Ana, with whom Rocio had apparently developed good rapport, should be the one to continue helping her. As for Ana, she said she found Rocio strong and weak at the same time. Ana admired Rocio's courage for taking care of her entire family, including

her granddaughter, but was concerned by Rocio's indecision about the amniocentesis. This concern moved her to offer unconditional support.

Kelly said she was surprised by Rocio's change of mind about amniocentesis, but satisfied that Alberto had participated in the genetics consultation, and glad he had been able to 'help his wife to make the decision.' She admitted she found Rocio 'high strung' and 'difficult to communicate with.' She said she had noticed Rocio looking distant and seeming upset during the consultation, reactions she attributed to Rocio's 'attitude.' 'Some patients only want to hear good news,' she observed. 'She came to have the amniocentesis and get rid of all her problems . . . . Knowing there was a slight possibility of bad news made her get defensive.' She continued, 'I [could feel] she didn't want to talk any more, so I asked her bluntly if she wanted to have the test or not . . . . In the end, I know that it is always their decision. They are the ones who have the final word . . . . I don't want to feel guilty that I made the decision for them [patients] and later they regret it.'

#### ANALYSIS

Researchers have found that patients' expectations for their clinicians and what will transpire during a clinical encounter often go undetected by clinicians (Freiden, Goldman, & Cecil, 1980). Heeding Lazarus's (1988) challenge that research on patients and clinicians focus on their social interaction and the broader life experiences they bring to a clinical encounter, we followed Rocio's lead and closely analyzed whether the expectations she and her clinicians brought to the interactional arena were met, and if not, what were the consequences. From our interviews, we learned that Rocio's expectations for the history-taking were generally satisfied with regard to finding friendly Spanish-speaking clinicians as she had in her neighborhood prenatal clinic. She was disappointed and bothered, however, by Maria, the medical assistant's insistence that Alberto be included in the genetic consultation because she only wanted him to 'see the baby' and she felt things get even worse when they met with Kelly, the genetics counselor (see sections *Actors and Their Expectations*, *History-taking*, *Genetic Consultation*). This mix of unexpected circumstances triggered feelings of antagonism in Rocio that we argue caused both her withholding of relevant medical information and changing her mind about amniocentesis (see sections *Genetic Consultation*, *Ultrasound*, *A Reflexive Account*).

The competing alliances that formed around the couple also clearly contributed to the patterns seen. Yet taking the lead from Rocio, we suggest that the antagonism she felt toward Alberto, Kelly and Bree was less a reaction to their insensitivity than to the fact that the genetic consultation

was not proceeding as she had expected. She reacted by shutting down communication (cf. Triandis, Marín, Lisansky, & Betancourt, 1984) and three times rejecting the amniocentesis, because she perceived that the antagonistic group wanted her to have it regardless of her own worries and concerns. She later changed her mind and agreed at once to have it when the offer was presented by the translator, who positioned herself as Rocio's ally (see sections *Actors and Their Expectations*, *History-taking*, *Genetic Consultation*). Contrasting the clinicians' perspectives with Rocio's on what transpired, we find reasonable concordance with Rocio's own perspective. This reinforced our view that Rocio's unmet expectations triggered emotions that led her to change her mind about amniocentesis (see section *A Reflexive Account*).

To suggest, however, that the interactional problems we observed were due exclusively to actors unmet expectations and the feelings they produced, is to posit a far too unidimensional view of social process. As the earlier material shows, other factors were also at play, including clinicians prioritizing a norm of professional neutrality and their assumption that reproductive decisions should be made by the couple, not just the woman. In addition, Rocio's own after-the-fact insistence on the importance of her unmet expectations in determining the behavior we observed may largely be rationalization, but there is no doubt that her day at the genetics clinic evoked a wide range of powerful emotions. She felt upset, frightened, threatened, challenged, pushed, unheard, and doubted – but she also felt cared for and protected. Independent of expectations, these emotions, in and of themselves, clearly influenced the interactions we observed. Moreover, given that the chief shortcoming of the case study approach is the difficulty in generalizing from its findings, the next step is to systematically test these results on a larger, more diverse sample. Still, we hope we have here shown that according closer attention to the expectations both patients and clinicians bring to a medical encounter and the emotions they produce, can better illuminate and improve processes associated with reaching medical decisions.

## CONCLUSION

Successful clinical communication is problematic not simply for the reasons usually given (e.g. too many patients, too little time, incongruent backgrounds), but due to the diverse and often ambiguous expectations patients, family members and clinicians themselves bring to clinical encounters. These considerations are further compounded by the mixed, opaque and often-contradictory emotions that may erupt during a medical consultation when expectations are not met. In the frequently tense context of genetic counseling, expectations, emotions and attitudes

undoubtedly affect clinicians' approaches as much as they do clients' plans and choices for action.

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### NOTES

1. Key to sources of data:

A. Observation

1. Systematic observation of interaction between Rocio and Maria during history taking.
2. Systematic observation of interaction between Rocio, Kelly, Alberto and Ana during genetic counseling.
3. Systematic observation of interaction between Rocio and Bree during ultrasound procedure with Alberto also present.
4. Systematic observation of interaction between Rocio and Bree during ultrasound procedure with Alberto and Ana present.
5. Opportunistic observation of interaction between Rocio and Ana during genetic counseling and ultrasound with Kelly and Alberto present.
6. Opportunistic observation of interaction Rocio and Ana.
7. Opportunistic observation of interaction between Rocio and Alberto.
8. Participant observation with Rocio.
9. Participant observation of the general environment during Rocio's day at the genetics clinic.

B. Interview

10. Semi-structured interview with Rocio.
11. Semi-structured interview with Maria.
12. Semi-structured interview with Ana.
13. Semi-structured interview with Kelly.
14. Semi-structured interview with Alberto.
20. Informal interview with Rocio before genetic consultations.
21. Informal interviews with Rocio between genetic consultations.
22. Informal interviews with Rocio after genetic consultations.



23. Informal interview with Alberto before genetic consultations.
24. Informal interview with Alberto after genetic consultations.
25. Informal interviews with Maria during Rocio's day at the genetics clinic and subsequently.
26. Informal interviews with Kelly during Rocio's day at the genetics clinic and subsequently.
27. Informal interview with Bree following Rocio's ultrasound.
28. Informal interview with Ana following Rocio's amniocentesis.

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