

The Roles of Trust and Cross-Cultural Miscommunication in Clinical Decision-Making

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Abstract / Resumen

This paper explores the emotional world of a recent Mexican immigrant who lives in Los Angeles and is awaiting the results of the amniocentesis she has ambivalently agreed to. She is 45 years old and has given birth to two children with severe disabilities and two who are apparently normal. We focus our analysis on the woman's reactions and feelings during the nine days she spends waiting for the test results. We show that the standard prenatal genetic clinical protocol aimed at providing medical education and requiring professional neutrality and emotional detachment left the woman feeling rejected and subsequently unwilling to seek information or support from her clinicians. We find that while the intent of a protocol of neutrality is to enable patients to make informed decisions without feeling pressure from clinicians, some women want greater emotional engagement. We argue that professional neutrality can inhibit patient-clinician communication, hamper medical education, and ultimately detract from patients' ability to make informed medical choices.

El presente artículo explora el mundo emocional de Rocío, una inmigrante mexicana, quien se encuentra esperando los resultados de una amniocentesis que aceptó hacerse, a pesar de las dudas sobre la credibilidad y utilidad de la misma. Rocío, de 45 años, tenía ya otros hijos, dos con anormalidades severas y dos aparentemente sanos. Centramos nuestro análisis en los sentimientos y reacciones durante los nueve días que transcurren mientras espera el diagnóstico. En este trabajo mostramos cómo la forma de presentar la información médica puede llegar a entorpecer la toma de decisión de un paciente. El protocolo genético tiene por meta proveer información médica manteniendo una cierta distancia profesional y emocional. Estas condiciones hacen que, en nuestro estudio de caso, la paciente se sienta rechazada y sin deseos de acercarse al personal médico, ya sea en busca de apoyo emocional o información que aclararía sus dudas. Creemos que, mientras el objetivo de la neutralidad profesional es asegurar que el paciente decida con los conocimientos adecuados y, a la vez, sin sentirse presionado, algunas mujeres preferirían un mayor acercamiento emocional por parte del personal médico cuando deben decidir sobre pruebas o tratamientos. Creemos que la neutralidad profesional puede llegar a inhibir la comunicación médico-paciente, dificultar la comprensión de la información y, por último, obstaculizar la habilidad de tomar decisiones informadas por parte de los pacientes.

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Introduction

As the urban U.S. grows increasingly characterized by ethnic heterogeneity, prospects for misunderstandings in clinical communication become more common and the consequences more intense. Assumptions rooted in cultural stereotypes can cause communication between patients and clinicians to break down. On the one hand, clinicians may assume that “cultural differences” are leading patients to act in ways clinicians feel are counterproductive, although this is not necessarily the reason why. On the other, patients may withhold relevant information if they assume they will not be “heard” by clinicians who they feel do not “speak” their language, literally or metaphorically. Mattingly succinctly summed up the situation when she observed that today clinical worlds are often contested terrain and “in clinic encounters that cross race and class lines, worries over being misread constitute major threats” (Mattingly, n.d., p. 17). Mattingly shows how a series of misunderstandings between an African American mother of a gravely ill child and the physicians from whom she sought diagnosis and treatment caused a breach of trust that could never be repaired.

Our own work on clinical communication between Mexican-origin pregnant women who are offered fetal diagnosis and clinicians from diverse ethnic backgrounds similarly shows the devastating consequences lack of trust can engender (cf. Browner et al., 2003). To do so, we offer the case of a recently immigrated Mexican woman with a history of birth anomalies who sought prenatal diagnostic testing. Her clinicians’ efforts to maintain professional neutrality and not intrude on the woman’s autonomy — clinical stances previously unfamiliar to the pregnant woman — not only caused her to feel unheard, but also led her to question the accuracy of her test results. Her mistrust of her clinicians’ motives made the woman unwilling to seek information that could alleviate her deep anxieties and help resolve her concerns. We show that the emotions generated during the prenatal genetic clinical encounter inhibited the development of a trusting relationship between the woman and her

clinicians, which in turn affected her ability to make informed choices about the future of her pregnancy.

Medical decision making is usually analyzed using models of rational choice. Such models assume that patients act to maximize positive outcomes, however these may be defined (Lerner & Keltner, 2000; Lerner & Keltner, 2001; Loewenstein & Lerner, in press). Following Loewenstein and Lerner we seek to show that in medical decision making, in addition to “rational” considerations patients can also be moved, perhaps even more powerfully, by emotions and the presence or absence of mutual trust (Bertha, 1992; Geertz, 1962; Giddens, 1990; Triandis et al., 1984; Vélez-Ibañez, 1983).

Background

Since 1986 the State of California has offered all women who enroll in prenatal care prior to their twentieth week of pregnancy the option of a prenatal screening blood test (Crandall, Robertson, Lebherz, King, & Schroth, 1983; Cunningham, 1998). Women who screen positive, indicating the possible presence of a problem, may pursue additional testing (usually a high-resolution ultrasound or an amniocentesis) to determine if the fetus does indeed have an anomaly, the most common of which are neural tube defects and chromosome disorders (ACOG, 1996). This additional testing is offered at a state-certified prenatal diagnosis center along with a consultation with a certified genetic counselor. The genetic consultation typically lasts 30 to 60 minutes and follows a standard protocol: the genetic counselor elicits the woman’s reproductive and family history and outlines her options for additional testing. The counselor also describes the benefits (i.e., reassurance) and risks (i.e., possible miscarriage) of amniocentesis and the option of terminating the pregnancy in the event of a positive diagnosis.

Methods

The focus of this analysis is the conversations that took place between one of the project’s ethnographers (HMP) and the pregnant woman

we call Rocio (all proper names are pseudonyms) during the nine days she spent waiting for her amniocentesis results. Rocio is part of a larger sample of 156 women (120 couples) who were interviewed as part of a study on amniocentesis decisions by Mexican-origin couples in California (Browner, Preloran, & Cox, 1999). We conducted semi-structured, open-ended, face-to-face interviews, typically lasting about an hour. Our sample was drawn from a mix of 11 public and private prenatal clinics and 11 State-approved prenatal diagnosis centers. All of the women had screened positive on the prenatal screening blood test and had been referred for genetic counseling and further testing. We also observed 145 prenatal genetic consultations, 39 sonograms and/or amniocentesis procedures and interviewed 50 of the clinical personnel (genetic counselors, geneticists, family practitioners, OB-GYNs, perinatologists, nurses, health educators and translators) who worked at the sites from which we drew our patient sample.

Rocio and four others were chosen for additional in-depth data collection because they seemed particularly receptive (see Browner & Preloran, 1999, for more methodological detail). In Rocio's case, when asked if she would participate in our study, she said she was willing to be interviewed after receiving her amniocentesis results and added that the ethnographer could call her "to chat" while Rocio was waiting for her test results (*puede llamarme y podemos platicar mientras espero*). Therefore in addition to structured observations we conducted during the five hours Rocio and her male partner spent at the prenatal diagnosis center and two-hour long face-to-face interviews with both Rocio and her husband, we also had four half-hour, unstructured face-to-face follow up meetings and 16 brief (about ten minutes) telephone conversations (eleven initiated by the ethnographers and five by Rocio). All of these interactions occurred during the two months following Rocio's amniocentesis. Eleven of the 16 phone conversations and one follow-up meeting occurred during the nine days Rocio spent waiting for her amniocentesis results.

Context

Rocio is a 45-year-old mother of two healthy sons and a daughter diagnosed with schizophrenia. Her older daughter, who died when she was eight, had been born in Mexico with "heart problems" and possibly Down syndrome. Her current pregnancy is Rocio's second with Alberto, who has no children of his own. She aborted the previous one two years earlier because she felt their union was not strong enough although she told Alberto she had miscarried.

We meet while Rocio is waiting to be seen by Maria, a medical assistant, who will take her clinical history. She confides in us that she is interested in amniocentesis because of her age and her concerns about the significance of her positive blood screening test. She hopes an amniocentesis will reassure her and Alberto that this pregnancy is healthy but, if not, she will consider an abortion. At the same time, she is apprehensive about the risks of the procedure; neighbors and friends have cautioned her against it.

Rocio's day at the genetics clinic does not proceed uneventfully (Balzano, Preloran, & Browner, 2002; Browner & Preloran, 2001). She seems frightened by the direct questions she is asked about her family's medical history and looks extremely uncomfortable when Kelly, the genetic counselor, challenges certain information Rocio provides, such as Rocio's belief that her deceased daughter's medical problems were caused by an improperly administered injection and other medical services the daughter received in Mexico, and that the congenital health problems of a nephew and her daughter are unrelated. Moreover, she finds Kelly cool and quite unsympathetic when Rocio recounts the circumstances of her daughter's death. Rocio is also disappointed with her interactions with the ultrasonographer and disheartened by the fact that these two English-speaking clinicians seem warmer and friendlier with Alberto than with her, the patient. She feels neither are sufficiently sensitive to the weight of the decisions she is facing about whether to have the amniocentesis and, should it be positive, whether to abort the pregnancy.

By the time the ultrasound, which was inconclusive, is concluded, Rocio's reservations about amniocentesis outweigh the possible advantages. Despite Kelly's repeated offers, she decides that she would rather not have the test. Ultimately, under strong, direct pressure from Alberto and gentle prodding from Ana, a clerk enlisted to serve as an interpreter, Rocio eventually relents and the amniocentesis is performed. Ana's openness and warmth, her friendly attitude when she offers to help Rocio find a place for the delivery, and her emotional account of her own amniocentesis experience and the beautiful son she now has, seem to have helped Rocio decide to have the test.

She returns home physically and emotionally exhausted — and unnerved by the sharp disagreement she and the ultrasonographer had had over Rocio's date of conception. Now she is becoming worried that the amniocentesis result will be incorrect because the information on which it is based is inaccurate. These worries weigh heavily and even grow during the nine days Rocio spends waiting for her amniocentesis results. But she declines the ethnographer's repeated urgings to phone the genetics clinic for emotional support or to get her questions answered.

We argue that when Rocio's expectations for empathic communication with the English-speaking clinicians went unmet, she became mistrustful of their motives. We show below that Rocio's narratives underscoring distrust in the clinicians' intentions and her doubts about the accuracy of the results emerge during her first day of waiting and continue throughout the waiting period. Other initial themes that emerge also re-appear in the days that follow: reports of a deep sense of sadness, feelings she was regarded only as "a number" at the clinic, and her unwillingness to discuss these feelings as well as her concerns about her physical condition with them. In addition we seek to explicate the importance of analyzing patients' clinical experiences and their consequences within the larger life contexts in which they occur.

Day One

When she calls, Rocio sounds very depressed. She reiterates her concern that the amniocentesis will not be accurate because the ultrasonographer recorded "the wrong date" of conception. Shifting topics, she talks warmly about her interaction with Ana, the interpreter, "She was there holding my hand to ensure I would keep my strength," and adds that when she tried to call the clinic earlier she learned that Ana would not be at work that day. That and her similarly unsuccessful effort to reach Maria, the medical assistant and only other person at the genetics clinic with whom she had felt rapport, have led Rocio to conclude that there is no one at the clinic who has any interest in helping her.

Rocio adds that she found the genetic consultation very disturbing and she now is convinced that her fetus has Down syndrome. She explains that by the time she got home after the amniocentesis she had begun to feel contractions and went to bed as a precaution against miscarriage as the doctor had advised. She has spent all day today in bed as well and as the hours drag by she is tormented by dark thoughts about the 'baby's' health. Rocio's affect and her remarks are of sufficient concern to the ethnographer to lead her to repeatedly suggest that she call Kelly, the genetic counselor and also request psychological referral. Both suggestions are disregarded. Rocio justifies her lack of interest in further communicating with the clinic with comments that reflect lack of confidence: "[There's no reason to call] -- they will say, 'Everything is going to be OK' -- but if everything is going to be OK, why did they send me to do that [amniocentesis]?" Further conversation on the subject makes it clear that Rocio is unwilling to contact any of the other clinic staff; she says she feels comfortable talking only with Ana, who is unavailable.

Day Two

Rocio calls the ethnographer "to say hello" but does not reach her. The ethnographer calls right back and Rocio warmly expresses appreciation for "returning the call so soon" and for talking with her about her medical experiences "openly and frankly". When the ethnographer suggests

that Rocio seek help for her depression by calling the genetics clinic, Rocio corrects her saying, "I'm sad, not depressed." She adds, "What are they going to tell me? [They will say] I should wait and think 'positive' but I prefer frankness and [talking with people] who openly show me their feelings. [This is why] I like talking with you [better]." She remains unwilling to contact the genetic counselor, explaining, "They don't listen to me. Look, they do not believe in me. They believed what the ultrasound said and not what I said [regarding the date of conception]." She has also become skeptical about the genetic clinicians' intentions, saying "Who knows why they are so insistent on saying that one needs those tests?" (*Vaya uno a saber por que insisten tanto que uno necesite esas pruebas*). They tried to convince me to have the test, but once I did, they are not interested in talking to me."

Throughout most of today's conversation, Rocio's voice sounds sad; often she seems on the verge of tears, but her tone changes to frustration when talking about her experiences at the prenatal genetics clinic. She again says she genuinely doubts that the amniocentesis will be accurate and now she is also beginning to doubt the accuracy of the ultrasound. She adds she is no longer sure that she will abort the pregnancy if the amniocentesis is positive because it may be erroneous: "If the clinicians considered the 'wrong day' of the conception, how could the results be one hundred percent correct?" At this point, she again mentions that she had tried to reach Maria and that she never called back. When the ethnographer suggests she instead try to contact Kelly, the genetic counselor, Rocio says she will consider it.

She also describes a recent conversation with Lucia, an old friend from her hometown of Mexicali. Lucia has encouraged Rocio to continue the pregnancy and have faith that God gives only burdens one can bear (*Dios sólo da el peso que podemos cargar*). With faith, Lucia had added, everything will become "possible to handle" and that "mothers always love their children," even those with Down syndrome. Rocio says that talking with her friend lifted her spirits, adding "these days" -- referring to this

period while she is awaiting her amniocentesis results -- she is more eager than ever to be surrounded by "spiritual people" such as Lucia who sympathize with her concerns and give her hope. She adds that one reason she is reluctant to contact the genetics clinic is because the staff lacks empathy, "The *guerita* [the blond one, referring to the genetic counselor] is too cold... one can't talk with her." "Because she speaks no Spanish?" asks the ethnographer adding, "but you know that translators are available." Rocio clarifies, "It is not because of the English... it is that she is, I don't know... I don't feel comfortable (*no me hallo*) with her. She questions everything; she doesn't believe in me."

Later in the conversation, Rocio mentions that to alleviate anxiety she creates images in her head that she calls daydreams (*ensoñaciones*). The one that has brought her most comfort is of a happy, healthy baby playing in the grass. As they say goodbye, the ethnographer asks if she might visit Rocio the next afternoon. Rocio agrees.

Day Three

The ethnographer arrives to find Rocio's physical appearance markedly changed from when they first met three days earlier. Today Rocio appears unkempt and much older. Grimly she reports that she is haunted by the information she got at the clinic about her daughter and nephew's illness (both showed signs of genetic anomalies) and she now feels almost certain that the child she is expecting will have the same problem. She is now convinced that the amniocentesis will be positive but even if not, she herself "feels baby is coming with problems" and wonders whether it would not be better to end the pregnancy rather than bring a child into the world "only to suffer?"

She explains she has become unable to concentrate or function and that all she does is lie alone in her darkened bedroom and cry. She is afraid to turn on the TV because images of healthy children make her feel sorry for herself. She has even hired a full time babysitter to care for her granddaughter. She says she initially turned down her daughter's invitation the

previous day to shop for new baby things, but then thought better of it and asked her daughter to go without her: "I thought it over and I realized that it is my baby and I have to love him in any way he comes" (*nazca como nazca tengo que quererlo*). When the ethnographer interrupts saying, "That means you will have this baby even if the amniocentesis is positive," Rocio response is ambiguous: "I am not sure... but yes... [I decided to continue because] it is too late [in the pregnancy] to terminate, besides, how can I be sure of the test result? ... What happens if they made a mistake?" The ethnographer's repeated suggestions that Rocio contact the genetics clinic for clarifying information continue to be disregarded: those clinicians make her uncomfortable, she says, and she does not have confidence in them. Brightening briefly, she asks if the ethnographer would call the clinic to try to correct the error of the "wrong date" of conception and seems disappointed when the ethnographer politely declines, "It is a pity," Rocio softly says, "I thought they would pay more attention to you and that it wouldn't be difficult for you to do it."

Day Four

Rocio calls the ethnographer to say she is still concerned about what she will do once she gets the amniocentesis result but quickly and agitatedly adds that there is a new family crisis. Alberto has called from Mexicali where he is overseeing construction on Rocio's new home. To help pay for the project, the family rented the two finished rooms to two young men who have just been charged with drug dealing. Police have seized the house and Alberto fears they will lose it. Rocio tells the ethnographer that she lacks confidence in Alberto's capacity to deal with legal issues and she has decided to make the trip to Mexicali "to save" her home. She asks the ethnographer about the risks of miscarriage, saying she fears that the potholes in the Mexicali roads could cause her "to lose the baby." When the ethnographer replies that she does not know about the risks of miscarriage and that Rocio should call the genetics counselor, Rocio asks the ethnographer call instead because her higher status would enable her to get more accurate information. Continuing, she explains that Anglo clinicians usually have an easy life in

the States and it would therefore be impossible for someone like her genetic counselor to understand the urgency Rocio feels about going to Mexico to save her home. Rocio adds that she fears if she does call, she will be advised not to travel.

This conversation leads the ethnographer to conclude that Rocio has now decided against ending the pregnancy. She asks what led to the change. In part, says Rocio, it was due to her last *ensoñacion* in which she again saw the image of a healthy, blond boy happily running through green grass. She now is certain that the ultrasonographer made a mistake about the date of conception and so the amniocentesis result will be meaningless. She has decided to continue her pregnancy "no matter what."

Day Five

When the ethnographer speaks with Rocio today, the urgency of the Mexicali trip has receded; the police have decided only to arrest the two renters and will allow the construction to continue. Rocio sounds more relaxed and again brings up her *ensoñaciones*: in her dreams she keeps seeing a happy and healthy baby, albeit with Down syndrome but nevertheless "beautiful," the physical characteristics associated with Down syndrome barely noticeable. She has "resigned herself" to accept God's will and she feels deep relief. She remains certain that she will continue the pregnancy regardless of the amniocentesis result, adding that as time has passed she has become even more convinced that its result will be meaningless because the ultrasonographer recorded "wrong date" of conception. The ethnographer's efforts to get Rocio contact the clinic to discuss the meaning of having recorded the "wrong date" again fail. Rocio says she does not want to talk with those clinicians because she does not trust them, "It is horrible, one doesn't know what to do, because there [in the clinic] they said that nothing is 100% certain, and with me it's even worse]... they even made a mistake with the dates. If they call me and say the baby is coming with an abnormality, what am I going to do? Do I have to believe them? Do I have to do something [abort]? In the end, it is better not to believe in those tests...."

Day Six

Today Rocio's mood is somber. She says she still plans to continue the pregnancy but she is even more convinced that she will have to care for a child with anomalies, "I feel that this pregnancy is different from the last one, it does not move, it seems that this child does not have energy....With my daughter [who likely was also born with Down syndrome] it was the same, she moved very little." The ethnographer suggests that Rocio call the clinic to ask whether fetal movement is a sign of health. Rocio replies by saying there is no need because she will continue the pregnancy in any event, "[My friend Lucia] told me that many times these babies look very beautiful (*"muy bonitos"*) and there is no way to know they are mongoloid (*"mongolitos"*).

Day Seven

There are practically no field notes today. Relatives visited Rocio and she sounded relaxed and happy in the brief phone conversation she had with the ethnographer.

Day Eight

Rocio is very depressed. She explains she is being pressured by her older son to consider an abortion "for the good of the baby and the entire family" if the amniocentesis is positive. Alberto has called from Mexicali to postpone his return because the situation with the police and the drug dealers has deteriorated. Once again Rocio is very worried about losing the house. Although she still fears she could miscarry on "those bumpy roads" in and around Mexicali she has decided she must go and will leave the next morning. She asks if the ethnographer would call the clinic the following day to request the results of the amniocentesis, adding that she herself has already called to ask to authorize release of the test result. Once the ethnographer has the result she wants her to immediately call her in Mexico since Alberto is "very interested" in learning the diagnosis. The ethnographer agrees to this.

Day Nine

In the morning, Rocio appears in deep turmoil. She tells the ethnographer she awoke feeling ill and decided to cancel her trip. She says she

spent a terrible night worrying that she might die if she went into labor on the road because she "does not know anybody." She fears the new baby could have schizophrenia since her (surviving) daughter was diagnosed with it and the psychiatrist who treated her had mentioned the possibility that the disease could be hereditary. She also brings up her feelings of guilt from her previous abortion and her concerns that the diet pills she took at the beginning of this pregnancy that could have harmed "the baby."

Later, in an early evening call, Rocio tells the ethnographer she just learned that the amniocentesis indicated that the pregnancy was free of genetic anomalies. Yet she remains doubtful. She wonders how a patient like her, with a positive prenatal genetic blood test, an inconclusive ultrasound and a family history of abnormalities could receive a negative amniocentesis and concludes "that the wrong dates spoiled the test (*la fecha equivocada ensució la prueba*) or "the results could be someone else's" (*pueden ser los resultados de otra persona*). The ethnographer's suggestions that Rocio call the clinic to discuss her concerns are, as in the past, disregarded. Instead she adds that she was resolved to continue the pregnancy even before receiving the amniocentesis result. From now on, she continues, she plans to focus on two wishes: to save the Mexicali home and to have a "strong" baby. In time, we learn that both are fulfilled.

Discussion

Mattingly and Lawlor are correct when they observe that patient-clinician communication is an inherently fragile endeavor, even when both parties enter the clinical arena open and trustful of the other's motives and intentions (Mattingly & Lawlor, 2001). Like Mattingly (n.d.) we sought to show that there are additional challenges inherent in cross-cultural clinical communication that make educating patients and clinicians as well as creating and maintaining trust more problematic still. The strong emotions such encounters can produce in both parties often play a defining role when trust fails.

We suggest that the emotions Rocio and her clinicians experienced during the prenatal genetic clinical encounter eroded mutual trust and influenced Rocio's decisions about her fate of her pregnancy. For example, the lack of interest Rocio repeatedly expressed in reestablishing communication with the English-speaking clinicians was justified by her skeptical comments underscoring mistrust of the information they could provide. Her narratives clearly indicate that despite much indecision during the days she waited for test result, she eventually decided to continue the pregnancy regardless of what the amniocentesis showed, that is, she had no confidence in the clinical findings. The paramount importance of trust as the precondition for meaningful clinical communication was further evidenced in Rocio's genuine interest in contacting Maria and Ana, the staff who she felt were more frank ("*francas*"), that is, more open and sincere.

What made Rocio so skeptical about the accuracy of the ultrasound and amniocentesis? Elsewhere we suggest that unmet expectations on the part of both Rocio and English-speaking clinicians made the medical encounters tense (Browner & Preloran, 2002). Rocio anticipated a quick and private consultation that would reassure her that the pregnancy was healthy or help justify an abortion. Instead, she found herself subjected to an exhausting five-hour ordeal with no reassurance at its conclusion – in fact she experienced the extreme opposite of reassurance, intensified worry. She found herself treated by an ultrasonographer who ignored the information she gave about her date of conception and who silenced Rocio twice, once when complained that the room was too cold and again when she wanted to talk about the fetal image that appeared on the screen. Rocio was in addition assigned a genetic counselor who she found impersonal and who, like the ultrasonographer, challenged the facts as she presented them. At the same time, in contrast to their own initial expectations that Rocio was highly motivated to undergo amniocentesis, the clinicians found a somewhat defensive and non-compliant patient. They reacted by becoming more distant and delegating Ana, the interpreter, whatever

responsibility she might be willing to take in building rapport with Rocio. It was in fact Ana who convinced Rocio to acquiesce to amniocentesis after she turned down Kelly's repeated offers.

Acquiescing to amniocentesis could have been the end of our history but it sparked an equally dramatic chapter: the nine days Rocio spent waiting for her amniocentesis result. During this period, distrust of the English-speaking clinicians and Rocio's resultant concerns about the meaning and accuracy of the test results intensified. Certain that the amniocentesis would be based on erroneous information, Rocio grew unwilling to use its result, should it prove positive, to help in the decision she knew she would be faced with about whether or not to terminate the pregnancy. By contrasting Rocio's expressions of antagonism toward the English-speaking clinicians with the rapport she felt toward the Spanish-speaking translator, we can begin to see that the professional neutrality espoused by the former seems to have shrunk rather than broadened Rocio's reproductive options.

The case study approach can often result in more questions than answers and Rocio's is no exception. We know that she decided to continue her pregnancy and that she says she would have done so regardless of what the amniocentesis revealed. Yet we cannot know what in fact she would have done had she tested positive. Alvarado and Alvarez, both prenatal genetic service providers, estimate that more than 70% of their Latino patients end their pregnancies following a positive amniocentesis (Alvarado, 2003; Alvarez, 2003; cf. Cunningham, 1998). Whether the women decided to do so prior to testing or did not plan to do so but later changed their minds is unknown. We also do not know what the dynamics of the medical encounters would have been if Rocio had attended without the threatening presence of her husband. And, finally, would more trust have been engendered if Rocio had been able to communicate directly with the clinicians without the aid of a translator? Would having done so led to fewer

misunderstandings? (Elderkin-Thompson, Silver & Waitzkin 2001; Flores, 2003)

What our data do show is that Rocio's reproductive reality was painful and complex, and genetic issues made this reality even more so. The strong emotions Rocio and her genetic service providers experienced during the clinical encounters not only contributed to miscommunication at the genetics clinic but carried over into her nine days of waiting -- interfering with her ability to make an informed medical decision about her pregnancy. We conclude that it was Rocio's emotions -- fear and her need for reassurance, trust and distrust - - more than the genetic information she was

offered at the clinic that were the main forces that produced the emotional roller coaster Rocio endured over whether to terminate or continue her pregnancy.

A first step toward improving patients' ability to make informed medical decisions would be to recognize that patients' and clinicians' prior expectations play an important role in the development of trust and rapport and that without these, misunderstandings are inevitable. With Latino patients, at least, limiting the professional distance within which prenatal genetic services are offered would help create conditions that could lead to more meaningful medical choices.

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