## Are Good Intentions Good Enough?: Informed Consent **Without Trained Interpreters**

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**OBJECTIVE:** To examine the informed consent process when trained language interpreters are unavailable.

BACKGROUND: Ensuring sufficient patient understanding for informed consent is especially challenging for patients with Limited English Proficiency (LEP). While US law requires provision of competent translation for LEP patients, such services are commonly unavailable.

DESIGN AND PARTICIPANTS: Qualitative data was collected in 8 prenatal genetics clinics in Texas, including interviews and observations with 16 clinicians, and 30 Latina patients. Using content analysis techniques, we examined whether the basic criteria for informed consent (voluntariness, discussion of alternatives, adequate information, and competence) were evident for each of these patients, contrasting LEP patients with patients not needing an interpreter. We present case examples of difficulties related to each of these criteria, and compare informed consent scores for consultations requiring interpretation and those which did not.

**RESULTS:** We describe multiple communication problems related to the use of untrained interpreters, or reliance on clinicians' own limited Spanish. These LEP patients appear to be consistently disadvantaged in each of the criteria we examined, and informed consent scores were notably lower for consultations which occurred across a language barrier.

CONCLUSIONS: In the absence of adequate Spanish interpretation, it was uncertain whether these LEP patients were provided the quality and content of information needed to assure that they are genuinely informed. We offer some low-cost practice suggestions that might mitigate these problems, and improve the quality of language interpretation, which is essential to assuring informed choice in health care for LEP patients.

KEY WORDS: informed consent; language barriers; genetic counseling; Latinas.

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• iven the increasing technical sophistication of diagnostic and treatment procedures, combined with a growing emphasis on patient involvement in health care decisions, 1-4 achieving sufficient patient understanding to assure informed consent for clinical procedures is challenging under the best of circumstance.5-7 It is even more difficult with patients who speak little or no English; a population which currently numbers more than 21 million people in the United States.<sup>8</sup>

US federal antidiscrimination laws require that health care facilities receiving federal funds provide professional interpretation services for their Limited English Proficient (LEP) patients.9 However, this mandate is rarely enforced, and because virtually no funding has been earmarked to cover these services, clinicians commonly rely on ad hoc translation strategies, which can seriously compromise the quality of clinical communication. 10-13 In this paper, we present findings from a qualitative study of prenatal genetic consultations with Latina women in South Texas, and examine the content and quality of communication in seeking their informed consent for amniocentesis when trained Spanish interpreters were unavailable.

#### **BACKGROUND**

Limited English Proficiency refers to individuals whose primary language is not English and who have limited ability to read, write, speak, and understand English. 14 Many LEP patients receive medical care in poorly funded public clinics where translated documents or trained language interpreters are simply unavailable, and untrained staff or family members are commonly called upon to bridge that gap. According to the National Council on Interpreting in Health Care (NCIHC), quality medical interpretation calls for accuracy, confidentiality, impartiality, respect, cultural awareness, role boundaries, professionalism, professional development, and advocacy;15 goals that are likely to remain unmet when relying on lay volunteers and untrained staff. The interconnection between poor language interpretation and breakdowns in health care quality and access has received a good deal of attention in the medical literature (for a comprehensive review, see Flores<sup>16</sup>). Ad hoc interpreters often lack sufficient bilingual fluency and medical vocabulary to translate complex health concepts accurately and completely. This can result in serious communication problems, including misinterpretation, inaccurate or incomplete information, and loss of privacy and of cultural idiom, affecting all aspects of care from accuracy of diagnosis to patient comprehension and adherence to medical recommendations.  $^{13,16\mbox{-}24}$ 

Obtaining patients' informed consent for medical procedures is a crucial clinical responsibility. A basic characteristic of informed consent is that it be an autonomous choice: the patient must be able to choose between options, according to her own values, which clearly requires information sufficient for rational choice. <sup>25,26</sup> Informed consent requires that patients receive adequate information, and that they understand it well enough to assess attendant benefits and risks. <sup>27–29</sup> Studies of health care for LEP patients consistently report that language barriers often compromise the already difficult process of assuring informed consent and confidentiality for these patients. <sup>4,13,17,21,23,30–33</sup>

While published lists of the criteria necessary for assuring informed consent vary in content and length, those we reviewed all include four basic elements: (1) the decision must be *voluntary*; (2) disclosure of relevant *information*, including the nature of the procedure, pros and cons; (3) discussion of the *alternatives*, including risks, benefits, and related uncertainties; and (4) the patient must be *competent* to understand relevant information and the decision at hand. <sup>5,7,25–28,34</sup> These four elements serve as the basis for our study.

When informed consent concerns a particularly trouble-some and emotionally charged question such as whether or not to have an amniocentesis, the necessity of assuring adequate communication is brought into high relief. While this is challenging even with English-speaking patients, in the absence of competent language interpretation, achieving informed consent for this procedure may be unattainable. Unattainable. Our study provides a rare opportunity to examine the informed consent process as it occurs across a language barrier, specifically in the delicate context of decision making about prenatal diagnosis.  $^{17,24,31,36}$ 

#### THE STUDY

#### Setting

In the course of a series of studies of prenatal genetic counseling practices in South Texas, we became interested in the quality and content of clinical communication in the presence of unaddressed language barriers, and particularly in how the process of assuring informed consent plays out under such conditions. Over a 5-year period, we conducted clinical observations and/or interviews at 15 of the 16 prenatal genetics specialty clinics in the region (for more discussion of the design and findings of the larger study, see Hunt and de Voogd,<sup>37</sup> Hunt et al.,<sup>38</sup> and Browner et al.<sup>39</sup>). We limit the present analysis to data collected at 8 clinics (1 public and 7 private), where patient and clinician subjects for this analysis were interviewed and observed.

Women determined to be "at-risk" for birth anomalies are referred to the study clinics from prenatal clinics across the South Texas region. Although we did not formally test their prior knowledge, it was clear to clinic staff and our own observers that most women arrived at the genetics clinics having little or no previous knowledge about amniocentesis. Nevertheless, they are expected to decide on the spot, whether they want the test. Clearly, the quality of clinician-patient communication can have a serious influence on the informed consent process for these patients.

Spanish is widely spoken in this region. Clinic staff estimated that as many as 40% of their patients speak Spanish as their primary language. None of the clinics had trained Spanish interpreters, and Spanish language consent forms were rarely available. Family members or friends accompanying patients, medical assistants, or other staff often acted as interpreters; in some cases, clinicians would rely on their own Spanish language skills. None of the clinics had any procedures for assessing the language skills of clinicians or interpreters.

#### **Data Collection**

We (LMH and KBDV) interviewed and observed a convenience sample of 16 clinicians who discuss prenatal genetic testing options with Latina patients. These included physicians, social workers, and certified genetic counselors. Three were native Spanish speakers, and the remainder self-rated their Spanish language ability as either "some," "a little", or "none at all." This was consistent with our impressions in our clinical observations. Assessment of the language skills of those we observed was made by unanimous consensus between the researchers (LMH and KBDV), and two bilingual graduate assistants, all of whom are fluent in Spanish, having lived and worked in a variety of Latin American countries. The interviews focused on the clinicians' strategies for offering prenatal diagnostic testing to Latina patients, as well as their approaches to language barriers (see Table 1).

We also interviewed a convenience sample of 30 patients of these providers, all self-identified Latina women whom we had observed being offered amniocentesis after an abnormal blood screening test. Interviews focused on their understanding and experiences with prenatal testing and for Spanish speakers, their impressions and experiences with language and interpretation issues. Patients were classified as having "no language problem" when their genetics consultation occurred between primary English speakers, or between primary Spanish speakers. They were classified as "interpreter needed" when their consultation involved either an untrained interpreter or a clinician who spoke limited Spanish (based on self-reports and our observations) (see Table 2).

All interviews consisted of standardized sets of open-ended questions, averaged 2 h in length and were tape recorded and transcribed. We also observed over 100 genetics counseling sessions where amniocentesis was offered. Careful field notes were taken to document clinician–patient interactions as fully as possible, giving special attention to translation issues when the interaction took place across a language barrier.

All study participants gave informed consent, after IRB-approved protocols. We explained the study to each clinician and patient we wished to observe and interview, in English or Spanish, according to their preference, and provided them with a written consent form, in their preferred language. They were asked to sign it, and given a copy to keep.

#### **Data Analysis**

We generated SPSS databases, including demographic variables as well as open-coded variables of the main questions covered in the interviews and observations. We established a method for standardizing and displaying interview data, as

Table 1. Selected Characteristics of 16 Clinicians Interviewed and Observed

Parameters		Number of clinicians	Percentage				
Gender							
	Female	7	44				
	Male	9	56				
Age (range	24–62; mean 35.8)						
	24–34	11	70				
	35–44	1	6				
	45–55	2	12				
	>55	2	12				
Ethnicity							
	Non-Hispanic White	9	56				
	Hispanic	6	38				
	African American	1	6				
Level of trai	ining						
	MD with genetics specialty (MFM or Peds)	3	19				
	MD: no genetics specialty (Ob/Gyn or FP)	7	44				
	Genetics Counselor (MS)	2	12				
	Other Prof.: no genetics specialty (MSW, MA, BA)	4	25				
Type of clin	ic						
	Public genetics specialty clinics	8	50				
	Private genetics specialty clinics	8	50				

illustrated in Miles and Huberman.  $^{40}$  The core of our analysis consisted of content analysis, as described by Bernard.  $^{41}$  We reviewed all clinician and patient interview transcripts, identifying the main topic areas and shared thematic patterns.

First, we summarized each interview, including pertinent quotations and summaries for each subject. Next, we made tables organized around the main topical areas of the interviews which were subsequently abstracted into higher-level

Table 2. Selected Characteristics of 30 Latina Patients Interviewed and Observed by Need for Interpreter in Consultation

	Language concordant		Interpreter needed		Total	
	n=19	%	n=11	%	n=30	%
Place of birth						
Mexico	4	21	11	100	15	50
United States	15	79	0	0	15	50
Years in the US						
0–3	0	0	3	27	3	10
4–7	1	5	5	46	6	20
8+	3	16	3	27	6	20
Does not apply	15	79	0	0	15	50
Age (range 17–41; mean 26.4)						
15–18	4	21	0	0	4	14
19–24	8	42	1	9	9	30
25–30	0	0	10	91	10	33
31+	7	37	0	0	7	23
Language of interview						
Spanish	2	10	11	100	13	43
English	17	90	0	0	17	57
Education years/formal						
1–11 years	6	32	7	64	13	43
H.S. grad or more	13	68	4	36	17	57
Marital status						
Single	10	53	2	18	12	40
Divorced	2	10	0	0	2	7
Married	7	37	9	82	16	53
Household income						
<\$10,000	1	05	3	27	4	14
\$10,000-20,000	9	48	4	37	13	43
>\$20,000	8	42	2	18	10	33
Patient does not know	1	05	2	18	3	10
Clinic type						
Public genetics clinic	9	47	10	91	19	63
Private genetics clinic	10	53	1	9	11	37
Amnio. Decision						
Accepted	15	79	9	82	24	80
Declined	4	21	2	18	6	20
Informed consent score						
0-2 (not informed consent)	6	32	10	91	16	53
3–4 (informed consent)	13	68	1	9	14	47

classifications based on thematic patterns found in the initial tables. Some initial language-related themes that emerged included: Rushed and Incomplete Translations; Inaccurate Translations; and Translators Promoting their own Agendas.

At all phases of the project, we cross-checked classification and coding decisions in conference sessions where the research team (LMH, KBDV, and the graduate students) discussed each case and reached consensus about the application of coding categories.

# Knowledge, Information, and Informed Consent Scores

For the current analysis, we developed rough measurements of the informational content of consultations, patient knowledge of amniocentesis and how well the basic criteria for informed consent had been achieved for each patient. This scoring system was based on eight informational elements the clinicians we interviewed consistently named as necessary to include when offering amniocentesis. The descriptions of the elements and our method for scoring are presented in Table 3.

#### **FINDINGS**

In observing consultations with Spanish speaking patients, we were often struck by the limited amount of information that was actually communicated. Interpreters often seemed to lack the linguistic fluency and/or the technical medical understanding necessary to provide an adequate interpretation. Text Box 1 illustrates this phenomenon.

#### Text Box 1.

In this case the clinician, a genetics counselor in a private clinic, would say a sentence or wo and the medical assistant would then repeat in Spanish, but much of what she told the patient was muddled or incorrect. Explaining where the needle would be inserted, the genetics counselor said: "It's always low on the belly, not in the belly button as some people have heard." This was translated as: "No es por el estómago, es por el ombligo." That is: "It's not through the stomach, it's through the belly button." Things get even more confusing as the genetics counselor explains the ultrasound procedure: "They'll look at the brain, and at the back of the neck..." The medical assistant translates this using the word "seso" for brain and "pescuezo" for neck, apparently unaware that in proper Spanish, these words are reserved for animals, and different words are used for these body parts in human beings. When the patient asks if she'll be put to sleep, the genetic counselor says she'll be given a shot to numb the skin, but the medical assistant tells the patient: "Si, te van a dormir, en el cuero. Usted no va a dormir, solo duermen el cuero." That is (literally): "Yes, they're going to sleep you in the leather. You won't go to sleep, only the leather they will

The clinicians were well aware of translation problems in caring for LEP patients. Many said using an interpreter was awkward and slowed things down and some said they abbreviated such consultations to compensate for the extra time. Several also had doubts about the technical knowledge and linguistic skills of the ad hoc interpreters.

Patients, in contrast, perhaps because they didn't know what should have been communicated in the consultation, were largely unaware of the poor quality of the interpretation they received. Nearly all needing a Spanish interpreter said they understood the information discussed in the consultation very well, and most were very satisfied with the consultation.

Patients' lack of awareness of interpretation problems belies the many serious deficiencies in communication that were observed with Spanish speaking patients. By considering case examples pertaining to each of the 4 informed consent criteria

#### Table 3. Calculation of Information, Knowledge, and Informed Consent Scores

#### Informational elements:

Informational elements which were consistently named in clinicians interviews as necessary to include when offering amniocentesis: (1) the nature of the anomaly, (2) the risk for the anomaly, (3) the amniocentesis procedure, (4) the risks associated with amniocentesis, (5) the information amniocentesis can produce, (6) reasons for doing amniocentesis, (7) that the test is optional, and (8) alternatives to amniocentesis. These eight elements formed the basis of our scoring system.

#### Information scores:

Observed consultations were scored for inclusion of each of these informational elements: "0" if the element was not mentioned, "1" for brief mention, and "2" for detailed discussion. These elemental scores were then totaled for each consultation, for an "information score".

#### Knowledge score:

Knowledge scores were based on the same eight informational elements. We reviewed patient interview transcripts and assigned a score for each informational element, as follows: "-1" for mentioning with significant errors; "0" for not mentioning; "1" for a brief or incomplete mention, and "2" for mentioning with accurate details. These elemental scores were totaled for each patient, for a "knowledge score".

#### Informed consent score:

We generated an informed consent score, based on the four essential elements we identified in the literature. We gave one point for each of the following conditions that were present: (1) voluntariness: in the observed consultation, the clinician was non-directive and made it clear that the patient could choose to accept or decline the test; (2) alternativity: the clinician discussed other testing options in the observed consultation; (3) information: the information score exceeded 60%; and (4) competence: the patient's knowledge score exceeded 60%. These points were totaled for each patient, for an "informed consent score".

we have identified—voluntariness, discussion of alternatives, adequate information, and competence—we will argue that inadequate Spanish interpretation may leave patients without sufficient understanding to make an autonomous informed decision about their medical care.

#### **Voluntariness**

A person acting voluntarily is one who is free from the manipulative or coercive influences of others.  $^{27}$  Standard genetic counseling protocols call for the clinician to be nondirective, allowing the patient to choose based on her own moral judgment, making the question of voluntariness especially charged in the field of prenatal diagnosis.  $^{42,43}$ 

Most of the consultations we observed were clearly nondirective, with the patient plainly being told that it was up to her to choose whether to have the procedure. While nearly all consultations without a language barrier were nondirective, this was so for only about half of the Spanish interpreted consultations. In some of these, the clinician failed to indicate that the procedure was optional; in others, the interpreter did not clearly translate that it was optional; and in still others, the amniocentesis was presented as simply the next step in the clinical process. Consider the case presented in Text Box 2, for example.

#### Text Box 2.

An Ob/Gyn resident is explaining the amniocentesis procedure to a 30 year old, Mexicanborn patient, with a clinic aide acting as interpreter. After translating the doctor's list of associated risks, the aide interjects in Spanish: "They do them all the time, dear, and rarely have a problem." The aide goes on translating: "We're going to do a sonogram to check the dates. If they are correct, then we'll do the amnio." The doctor signs the English consent form, the aide signs as witness, and hands it to the patient for her to sign, without further explanation. After the sonogram, the attending physician says in simple Spanish: "... There's probably nothing wrong; we're just going to do this test [the amnio] to be sure." Between the interpreter adding her own opinion, and the clinician's limited Spanish, the patient is never actually told that the test is optional.

Assuring voluntariness was also elusive in cases where the interpreter was a relative who took on the role of decision maker. In several cases, clinicians presumed the patient needed her husband's permission and would insist that she consult her husband before accepting the procedure. (For further discussion of such cultural assumptions on the part of the clinicians, see Hunt and de Voogd<sup>44</sup>). In the case presented in Text Box 3, we see the combined effect of presuming a dominant role for the husband and having him act as interpreter.

#### Text Box 3.

The husband, a construction worker, interpreted for the 29 year old patient, recently arrived in the U.S. The physician spoke directly to the husband, and didn't wait for him to repeat things in Spanish to the patient. When we interviewed her a few weeks later, she said she hadn't understood much in the consultation and felt she hadn't been permitted to decide for herself. She said: "I felt terrible because I couldn't understand what they were saying. When we left there I told my husband... I don't want you to say you speak English... I want to hear what they're saying, I don't want you telling them, 'Yes,' then later explaining everything to me.'"

#### **Discussion of Alternatives**

Assuring an autonomous choice also requires the discussion of alternatives, along with a general description of the related costs and benefits of each. 45 The code of ethics for genetic counselors states that counseling should "enable clients to make informed decisions, free of coercion, by providing or illuminating the necessary facts, and clarifying the alternatives and anticipated consequences". 46

Making an informed decision about amniocentesis requires patients to do a complex evaluation of the risks of a birth anomaly versus provoking a miscarriage, in the absence of safe, effective treatment options. 5,6,47,48 One might argue that not having the amniocentesis is a second option. However, when a patient is responding to the fear and uncertainty of an "at-risk" pregnancy, she may feel she lacks the authority to choose to do nothing, and must accept to protect the welfare of the baby. 5,29,48,49 We have reported elsewhere that we found this to be the case for many of the women in this study.  $^{37,38,50}$ 

A high-resolution ultrasound is routinely offered as an alternative to amniocentesis, and is preferred by some women because it is noninvasive.<sup>51</sup> An ultrasound cannot produce genetic information and is therefore less definitive than amniocentesis. However, high-resolution ultrasound can identify certain structural anomalies consistent with the diagnoses in question and is commonly offered as an alternative to amniocentesis.<sup>52</sup>

The patients we interviewed were nearly evenly divided between those given the option of a high-resolution ultrasound and those not. When considering those needing Spanish interpretation separately, we saw a great disparity. While this alternative was presented to most of those without a language barrier, only 1 woman needing an interpreter was given this option.

The case presented in Text Box 4 illustrates how consultations occurring across a language barrier were often limited in content, especially when no interpreter was available. In this case, the patient was given so little information that alternatives to accepting the amniocentesis were never mentioned.

#### Text Box 4.

The doctor, a senior resident, is counseling a 28 year old patient in his beginner's Spanish. Looking over the chart, he says:

[In Spanish] This all looks fine

[In Spanish] So what is the problem, doctor? [In Spanish] Well, it could be that everything is fine, or it could be a problem with the spine. We could do an amniocentesis. That would be more sure than the blood test, but nothing is 100% sure... But with the amniocentesis we will know more. [Pause.] Would you like to do the amniocentesis today?

The patient agrees. The doctor then goes over the English consent form, naming the possible risks in his elementary Spanish, then shows the patient where to sign and date the form, which she does. The amniocentesis was performed within the hour.

#### Adequate Information

The conditions for autonomous decision making require that patients be provided with the information necessary for a reasonable person to make an informed choice. 27,34 The information scores (described in Table 3) for the study group as a whole were nearly evenly divided between high scores (a score of 60% and above) and low scores (below 60%). When the scores were considered in terms of language issues, a different picture emerged. While nearly two-thirds of consultations with no language barrier had high information scores, only about a quarter of those needing interpretation had similar scores.

Often, in the Spanish interpreted consultations, we observed clinicians covering just the "high points" of what was ordinarily included in the genetics counseling consultations, as can be seen in several of the previous examples.

Allowing patients a chance to ask questions and have them answered is an important aspect of assuring they have adequate information.<sup>17</sup> This occurred only infrequently when the consultation involved Spanish interpretation. Commonly, patient interjections or questions were not understood or were ignored by the interpreter. As illustration, consider the example presented in Text Box 5.

The physician is speaking to a 29 year old patient, with an American-born nurse acting as interpreter. [In English] Tell her it was the Down's Syndrome part of her blood test that's not normal Nurse: [In Spanish] In your blood test, it is showing there is a possibility that the baby will have

[In Spanish] And other women who have this blood test, with the same result as mine, how many of them end up with babies who have Down Syndrome? Nurse: [In Spanish, without translating the question for the doctor.] It's only a risk, dear. It's not

saying that the baby HAS Down Syndrome.

The interpreter in this example doesn't address the patient's concern about the accuracy of the blood test, but instead clarifies that the screening test is not diagnostic. The patient's question goes unanswered, and she is left to conclude what she may.

### Competence

Competence is perhaps the most difficult of all the criteria to define and assess. In very basic terms, competence refers to the ability to make a rational decision. This requires that the person have sufficient understanding to reach an enlightened decision. $^{27,45}$  To assess patients' competence, we consider the knowledge they expressed in interviews: of the procedure itself, its attendant risks and benefits, and alternatives to accepting the test.

Patients' knowledge scores (described in the Table 3) were nearly evenly divided across the total study group, with about half having high scores (60% or more) and half having low (less than 60%). Those needing a Spanish interpreter were at a disadvantage, with about two-thirds having low knowledge scores as compared to low scores for about half of those without a language barrier.

While both groups understood the general nature of the amniocentesis procedure itself, the patients needing Spanish interpretations showed poorer understanding of the attendant risks and alternative options. For example, most of these patients did not express a clear understanding that amniocentesis could provoke a miscarriage, and many said they had not been told that terminating the pregnancy was an option should an anomaly be found.

The case example presented in Text Box 6 illustrates how unaddressed language barriers might engender patient misunderstanding and confusion.

#### Text Box 6.

A 4th year resident, relying on her very basic Spanish, is conducting the consultation because no interpreter was available. After briefly explaining the procedure and its risks, the doctor turns to writing up her notes, and preparing the consent form.

At one point, she stops writing to ask the patient, in Spanish, "You understand that your risks are breaking the bag, infection, losing the pregnancy?" Hearing this, the patient, quickly says, "Then no. I don't want to do it." The patient then asks, "Where do they take the liquid from? From the baby?" The doctor laughs loudly and answers, "No, no, no! It's very small the risk of losing it, only one in 200." The patient is silent for a moment, then says, "Yes, let's do it."

When we interviewed this patient a few weeks later, she said she had been told the baby "...was going to be born with Down syndrome," and that the main risk of the anniocentesis was that they could "stick the baby with the needle." She did not know that amniocentesis carries a risk of miscarriage, and could only describe Down syndrome in the sketchiest detail, saying the baby could have very small fingers, head, and eyes. She commented that the doctor had difficulty with the language, and this made it hard for her to understand everything.

Cases like this were not exceptional in our study. Often, what was actually communicated in Spanish was similarly attenuated by omissions and translation errors. But in these clinics, where time and resources were in short supply, and many patients were impoverished and poorly educated, might achieving the conditions of informed consent be uniformly illusive?

Meeting Basic Criteria for Informed Consent? To assess how well the overall criteria of informed consent were met in these consultations, we generated a composite informed consent score, (described in Table 3). As a group, patients were nearly evenly divided between high (3–4) and low (0–2) scores. When comparing scores between consultations needing or not needing Spanish interpretation, we found a striking difference. While more than two-thirds of those without a language problem had high informed consent scores, only one of the Spanish interpreted consultations met our minimum criteria for an autonomous informed choice.

#### DISCUSSION

We have considered a variety of ways that inadequate Spanish interpretation seems to interfere with achieving autonomous decision making for LEP patients. In the absence of trained interpreters, it was left to individual clinicians to find ways to communicate with these patients, including enlisting help from whoever happened to accompany the patient, using untrained staff, or relying on their own Spanish skills. Our analysis found these interpretations to be consistently limited in thoroughness, accuracy, and completeness. We have presented case material to illustrate how, despite clinicians' best intentions, such adaptations may fall short of genuine informed consent. Contrasting the experiences of patients who needed and those who did not need Spanish interpretation, we saw patients needing translation were consistently disadvantaged in the quality and content of their consultations.

Because we did not assess patient knowledge before the consultations, we have no way of knowing whether these differences exist outside the consultations themselves. However, given our observations of the general incompleteness of Spanish interpreted consultations, we are persuaded that they reflect the paucity of information provided in translated consultations.

This study has several limitations. While we have presented case materials describing how the use of untrained interpreters can seriously undermine the opportunity for informed decision making among LEP patients, our conclusions cannot be generalized beyond describing this particular group. This was designed as a purely descriptive study, using convenience sampling techniques, a small number of patients, clinicians and clinics, and encouraging spontaneous topics to be raised and discussed. Future research with representative samples would be necessary before any general conclusions could be drawn about a broader population. It would be especially informative to examine the effect of competing variables, such as education and income levels, which clearly are beyond our study design. It would also be very informative to compare consultations with trained versus untrained interpreters.

Despite federal regulations requiring clinics with significant numbers of LEP patients to provide access to professional interpreters, 9.53 many clinics serving minority populations operate under very tight budgets, and providing such services is patently unaffordable. In the current national atmosphere of growing intolerance and suspicion of foreign-born people, particularly Latinos, we must not lose sight of the moral and ethical cost of failing to address language barriers. We have raised a concern that this can amount to failing to assure the basic rights of LEP patients to give informed consent for medical procedures.

In the face of these challenges, there are some low-cost strategies that can be implemented to improve understanding and communication with LEP patients. For example, the cost involved in translating key documents, such as informed consent forms, into Spanish would be minimal. Clinicians and other staff could be tested for bilingual skills, especially where they involve medical terminology, and interpreting skills. 54,55 Staff who will be interpreting could be provided inservice training to learn proper vocabulary, and be taught the importance of "line-by-line" translations, as well as the importance of avoiding interjections. Clinicians could also be trained in how to effectively use interpreters and additional time could be scheduled for consultations requiring interpretation. Several recent articles outline promising models for such staff and clinician training. 20,54,56-59

Some states have adopted Medicaid codes that include compensation for language interpretation. Clinicians, who may be legally liable for failure to assure adequate interpretation in their clinics, could more avidly pursue such changes. <sup>21,23</sup> While the practices we describe will not completely erase the problems encountered when one works across a language barrier, they would surely improve the quality of language interpretation, an essential step towards the goal of assuring informed choice in health care for LEP patients.

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