

# What Latina Patients Don't Tell Their Doctors: A Qualitative Study

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## ABSTRACT

**PURPOSE** The treatment a patient receives is greatly affected by what he or she chooses to disclose to a physician. This qualitative study investigated such factors as culture and background that contribute to Latina patients' nondisclosure of medical information.

**METHODS** Participants were 28 Latina women living in Brooklyn. In-depth interviews in English or Spanish were conducted and documented by extensive notes. We used a grounded theory approach to find emerging themes, which were coded using a continuous iterative process.

**RESULTS** Six primary themes emerged: the physician-patient relationship, language, physician sex and age, time constraints, sensitive health issues, and culture and birthplace. Such qualities as compassion, caring, human interest, and kindness were important to many Latinas, who did not feel safe sharing information if these qualities were absent. Language barriers caused problems with physician-patient interaction, which were complicated by the presence of a translator. Physicians being male or younger could make disclosure difficult, especially around issues of sexuality and genital examination. Time constraints and cultural differences sometimes resulted in physicians' lack of awareness of sensitive areas that patients did not wish to discuss, such as sexuality, family planning, domestic abuse, and use of recreational drugs. Birthplace (foreign born vs US born) played a role in how the women perceived barriers to disclosure.

**CONCLUSIONS** Staff training in techniques for building rapport can foster better communication, increase empathy and compassion, and lead to the establishment of trusting relationships in which disclosure is more likely.

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## INTRODUCTION

The treatment a patient receives can be greatly affected by what the patient chooses to disclose to his or her physician.<sup>1-5</sup> Race has been shown to be a significant factor,<sup>5-7</sup> as has age,<sup>5</sup> physician sex,<sup>5</sup> language and education,<sup>6</sup> and immigrant status.<sup>7</sup> Culture and ethnicity also play an important role in what patients choose to disclose and in the manner in which they disclose it,<sup>7,8</sup> though additional studies are needed to show how these factors operate. Nondisclosure of information necessary for proper treatment can have a detrimental effect on patients' health.<sup>9</sup> Barriers to disclosure include patients' thinking that certain information is not important<sup>10</sup>; feelings of anxiety, stigma, and embarrassment<sup>11</sup>; and physicians not inquiring about certain issues, such as partner abuse.<sup>7</sup>

Even though many studies have explored impediments to communication between patients and physicians, Latina women were not well represented in such studies. Sankar and Jones<sup>1</sup> investigated women's deliberations related to disclosure, focusing on experiences with physicians in which women made a choice either to tell or not tell the physician something. Only 5 women (6%) of their sample, however, were Latina. Certainly, Latinas are represented in some studies of disclosure focusing on specific areas,

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such as intimate partner violence,<sup>12</sup> but a search of the literature found no studies of general considerations related to disclosure in health encounters. A better understanding of barriers to disclosure in Latinas could improve their health care outcomes. To this end, we chose to use the approach of Sankar and Jones<sup>1</sup> but to broaden it to investigate more general considerations affecting disclosure. The goal of this qualitative study, therefore, was to clarify which conditions reinforce nondisclosure of health information in clinical encounters between Latina patients and their physicians.

## METHODS

Participants in this study were Hispanic women older than 18 years living in the vicinity of Sunset Park, Brooklyn. Women aged over 18 years were chosen instead of women aged under 18 years and men because it was thought that their reasons for nondisclosure might be different, and the resources to carry out the study were not adequate for participants with widely divergent experiences. After approval by the Lutheran Medical Center Institutional Review Board, participants were recruited through announcements in a variety of educational classes at a neighborhood support center that offered case management but did not provide medical care. Interested women ( $n = 28$ ) volunteered. The interviewers obtained informed consent before conducting the interviews, reading the consent form to women who were illiterate.

In-depth one-on-one interviews were conducted using a semistructured interview guide with many open-ended questions designed to encourage interviewees to fully describe their concerns. The guide was based on that of Sankar and Jones,<sup>1</sup> and the overall structure of this guide was maintained. The guide first elicited demographic information, then general notions about medical confidentiality and disclosure, then more personal experiences with disclosing sensitive medical information in actual health care encounters, and finally additional demographic information. The focus of the guide was modified by adding questions that would elicit the reasons Latinas gave for nondisclosure in general (both participants' own reasons and their experience of the reasons of others), as well as their specific deliberations about disclosure. The guide included additional issues that might be relevant to some Latinas, such as the use of interpreters. Both the interviewers and the health center's vice president for cultural competence, who had many years of training and consulting experience in that field, made suggestions for revising the interview guide. The availability of English and Spanish versions of the guide allowed communication in the language with which interviewees were most comfortable.

The interviews took place in a private room at the Family Support Center and lasted from 30 minutes to 1 hour. Interviewees were given \$25 in cash at the conclusion of the interview as compensation for their time.

Our research team consisted of 1 female Ecuadorian physician not involved with our health care system (J.V.), 2 Latino resident physicians familiar with the patient population (C.D., born in Ecuador; E.C., born in Cuba), a medical student with a journalism degree (J.K., born in the United States), a community-based educator familiar with Latina culture and social needs (H.S., born in the United States), and a researcher with a decade of qualitative research experience (K.J.). The variety of perspectives of our team helped ensure a depth of understanding critical to study design and validity of results. A physician (J.V.) and 2 nonmedical staff of the Family Support Center were trained in techniques of qualitative interviewing and note taking in a 2-hour session. Interviewers were asked to take extensive notes and to enclose verbatim translations in quotation marks. Interviews were not recorded, transcribed, and translated because of lack of finances, but the notes were translated and transcribed by the interviewers. The author most experienced in qualitative research (K.J.) monitored interview notes to ensure that rich details were captured, to help identify new questions or modifications based on what was being learned, and to ensure that the interviews were conducted in a probing way that did not bias interviewees' responses.

Data were analyzed using a grounded theory approach in which explanations and theories about Latina women's disclosure patterns emerged from the interview data.<sup>13,14</sup> All coauthors identified themes in the data. As the interviews progressed, emerging themes were codified into a coherent list, first individually and then as a group at team meetings. Definitions and instances of themes were clarified in the group meetings to make sure all authors defined the themes similarly. To enhance reliability, several authors coded each interview manually, discussed themes found in the interviews in detail, and used group consensus to make sure all perspectives on the themes were represented in the written results.

## RESULTS

The 28 women who volunteered to participate in the study were born inside and outside the United States and varied by marital status, age, education, and socioeconomic status (Table 1). Six main themes (Table 2) emerged related to the disclosure of health information: the physician-patient relationship, language barriers, time constraints, sex and age differences, sensitive issues, and culture and birthplace.

**Table 1. Demographic Characteristics of the Interviewees (N = 28)**

Characteristic	% (n)
Age, y	
18-28	32 (9)
29-39	32 (9)
>40	36 (10)
Marital status	
Single, cohabiting	43 (12)
Married	39 (11)
Divorced	7 (2)
Separated	11 (3)
Widowed	0
Country of origin	
United States	29 (8)
Central America	54 (15)
South America	17 (5)
Languages spoken	
Spanish only	43 (12)
English and Spanish	57 (16)
Education level	
Illiterate	10 (3)
Grade school	25 (7)
Some high school, high school graduate	36 (10)
Some college, college graduate	25 (7)
Graduate degree	4 (1)
Raised in a religious tradition	
Yes	64 (18)
No	36 (10)
Visits to doctor in last year, No.	
0	17 (5)
1-5	43 (12)
6-10	25 (7)
>10	15 (4)
Doctor visits needed a translator, No.	
0	67 (19)
1-5	25 (7)
6-10	4 (1)
>11	4 (1)
Annual Income, \$	
<15,000	35 (10)
15000-24000	25 (7)
25,000-40,000	11 (3)
40,000-75,000	11 (3)
>75,000	7 (2)
Unknown	11 (3)

### Physician-Patient Relationship

Of the 28 women interviewed in this study, 26 discussed the physician-patient relationship. Above all, women said disclosure depended on developing a trusting relationship with their physician based on mutual respect, and their willingness to disclose health information decreased if they did not sense that their physician was compassionate. A 26-year-old woman from Mexico, for instance, said that a doctor needs

to "look for the patient's trust, and he needs to show that he pays me attention and he will take care of me." Some women expected a caring and compassionate physician-patient relationship to extend beyond the health encounter, such as in extending condolences over a death in the family or attending a funeral.

Without compassion, trust, and respect on the part of the physician, interviewees said they would not share information, and the level of confidence in their health care clinicians plummeted. Communication problems, such as being interrupted, could disrupt this trust. A woman from Mexico stopped trying to fully discuss her health issues with her doctor, saying, "They never ask you more than your symptoms, and when I want to share more, they cut me off."

Participants sometimes experienced lack of communication as violating their trust (and in the following example combined with invasion of privacy): "In my third delivery, the physician didn't tell me that there will be students watching. I was so embarrassed and angry." Physicians' emotional reactions to patients and insensitivity to patients' feelings could disrupt trust. Furthermore, some patients believed that their insurance status affected the physician's willingness to be compassionate. One interviewee recounted that she and her sister had adjacent appointments with the same physician. The sister had private insurance, and the physician treated her politely. When the time came for the physician to see the interviewee, his attitude shifted as soon as he found out her insurance status. The only major difference between her and her sister, and thus the only reason she could find for the abrupt change in his manner, was that she was covered by Medicare.

### Language Barriers

Language barriers often interfered with effective communication of health information to physicians and nurses, with interviewees' comprehension of procedures and treatment plans, and with their trust that their medical information would be kept confidential. Of the 28 women interviewed, 23 expressed difficulty disclosing information to their physician because of language.

Interviewees said that language problems sometimes caused nurses and physicians to react negatively, making patient disclosure less likely. Illustrating that not all language barriers are caused by the patient's lack of comprehension of standard English, 1 participant related an occasion in which the doctor became frustrated with her: "I couldn't understand what he told me. He had a really difficult accent, and he got upset because of that."

Translators were associated with major difficulties in disclosing medical information. Interviewees believed that their confidentiality was not protected when a translator was present and were often uncomfortable

**Table 2. Disclosure Themes and Concerns, Ranked by Frequency**

Themes	No.	Concerns
Physician-patient relationship	26	Physician lacks compassion, kindness, and politeness Physician cuts off patients when they try to explain Lack of interest shown by physician
Issue-related barriers	24	Patient fears retaliation from domestic abuser Patient feels that issue is not physician's business Patient feels unsure about benefits from disclosing information
Language barriers	23	Physician does not speak Spanish Patient feel uncomfortable when is a third person is in the room Patient feels like translator does not pass correct information Patient pretends to understand everything to avoid a translator
Cultural differences	19	Latino families do not talk about sex or related topics Physician made critical judgments of desire for larger families
Sex or age differences	15	Patient uncomfortable discussing sexuality or related topics with male or younger physicians Patient does not want genital physical examination by male physician
Time constraints	7	Encounter with physician is too short to establish rapport Physician focuses on treatment more than patient communication Patients leave without understanding information

with any third person in the room. An Ecuadorian woman said that she distrusted translators so much that if her doctor spoke only English, she would not attempt to communicate her thoughts and feelings: "I just accept what they will do to me." Inappropriate translators, such as family members or other patients could seriously compromise disclosure. A 61-year-old woman expressed frustration with the lack of availability of appropriate translators: "It is difficult because they don't speak Spanish, and I don't speak English. Then they need to look for a translator, or if they can't find one, I need to ask my relatives to go with me to the next appointment. That situation is really embarrassing."

### Time Constraints

Mentioned by one-quarter of the women interviewed, time constraints upon the health encounter also played a role in reducing women's disclosure of health information. The brevity of their visits diminished women's comfort with their physician, caused women to perceive that the physician was stopping their transmission of information by interrupting them, and hindered the development of a good doctor-patient relationship. A 23-year-old Mexican woman said, "I didn't feel comfortable with him, the meeting was too short and fast, ...he didn't pay attention to what I was saying, he didn't ask me my name, and he didn't introduce himself. He went directly to check me. It was the most uncomfortable situation."

Language issues and time constraints occasionally worked together to prevent disclosure. Sometimes patients pretended to understand the physician because finding a translator could take a long time. A few women even believed that patients used lack of

time so that they would not have to disclose embarrassing or sensitive health information during the health encounter. A woman from Nicaragua said that patients "take advantage that the time is short, so they can avoid the topic [sex] and don't talk too much."

### Sex and Age Differences

Differences in sex and age also created barriers to disclosure. Sex difference was a more common theme than age difference. Of the 28 women interviewed, 15 stressed that having a female physician made them more comfortable, especially for gynecological matters. These women stated that not only was it easier to discuss genital problems and

feminine and reproductive issues with a woman doctor, but also it was much more likely that they would be compliant with her health advice and not miss their appointments. Only a 64-year-old Nicaraguan woman mentioned age difference directly, saying, "I'm an older woman, and [sharing] my sexual life with a young doctor... it is not comfortable. I feel embarrassed."

### Sensitive Issues

Sensitive issues came up on their own as reasons not to disclose health information. Sex, sexual orientation, sexually transmitted diseases (STDs), genital issues and examinations, domestic abuse, abortions, information that adolescents feared physicians would disclose to their parents, and drug use were issues that women believed patients had difficulty discussing with the medical community. Of the 28 women interviewed for this study, 24 believed that these sensitive topics were difficult to share with health care professionals under most circumstances.

All 24 women who talked about sensitive issues mentioned difficulties discussing sex and STDs, and some believed that the Latino culture made it difficult to discuss sexual issues comfortably with physicians. This avoidance of sexual issues was present even in women who were interviewed in Spanish and had Spanish-speaking physicians. A 30-year-old Mexican woman said, "When you need to share about your sexual life, it is difficult. It is worse when the physician is a male... Our parents don't talk about sex at all. That's why I got pregnant." Most women interviewed did not link silence around sex with lack of education. They believed that most adults were knowledgeable about sex. Instead, they

believed that their culture regarded sex as a personal, intimate issue to be discussed only with one's partner and sometimes not even then. They particularly wished to avoid exposing children to the topic. Several women mentioned that a common strategy was to tell the doctor about a friend who had a problem related to sexuality when actually the patient herself had the problem.

Amplifying the effect of cultural background, some women did not want to disclose STDs in the medical setting because of the judgments they believed doctors and nurses would have. One interviewee who had had syphilis said that medical staff would "look at you like you are contagious" if you disclosed that you might have an STD. Another said that an "STD is secret information. A doctor may judge you or look down on you if you tell them about that." A small number of women implied that the wish to preserve the family at all costs also caused women not to disclose that they might have a sexually transmitted disease, even if the disease had been transmitted through the husband.

Interviewees also believed that patients who were dealing with domestic abuse would find it a difficult subject to bring up with health professionals, tending to either avoid such questions or lie. Confirming this finding, the 1 interviewee who had been a victim of domestic abuse said that she waited 3 years before she told her physician about the abuse. "In our society the women try to preserve their marriage until the last consequences," she said. "Our women think they will be rejected just because they are divorced...we need to preserve the family."

### Culture and Birthplace

Culture affected aspects of all of the above themes, with birthplace sometimes modifying these effects. Regarding the physician-patient relationship, for instance, many women placed a high value on a caring social interaction whether they were born inside or outside the United States. Likewise, slightly more than one-third of these 2 groups strongly expressed that being listened to and heard by their physicians was important. Many women from both groups stated that their cultural background made it difficult for them to discuss sexual issues with their physicians.

Even so, birthplace (ie, US born vs foreign born) seemed to influence some women's attitudes and preferences. Regarding physician sex, many foreign-born Latinas strongly preferred female physicians, with 14 interviewees expressing this preference spontaneously, whereas only 1 US-born interviewee expressed this preference, and 2 preferred male physicians.

Birthplace also was related to the anxiety around genital examinations and nondisclosure of genital problems to avoid examination, with 6 foreign-born women but

only 1 US-born woman expressing this concern. One woman born in the United States stated that she preferred a male physician because female physicians might assume that they knew how to conduct a genital examination in the best way, whereas male physicians, lacking such assumptions, might be more careful and respectful. Many foreign-born women, on the other hand, reported feeling far less embarrassed being examined by a woman.

Suggested by the tenor of the interviews but difficult to quantify, women who grew up in the United States differed from those born outside the United States in their emphases on aspects of the patient-physician relationship and communication. Some women born in the United States gave the impression that they regarded their doctor's role more as that of a paid professional, even though they still wished for a relationship characterized by warmth and compassion. One interviewee, for instance, told friends "to investigate the physician first before you take him as a regular. They should ask how long he has been in practice and did he ever have a lawsuit." Women born outside the United States, however, tended to trust the doctor's medical training and automatically respect him or her as the authority in charge of their and their families' health. What they most desired from the relationship was the physician's ability to empathize with and understand them. One participant summed up this sentiment in a simple statement: "I want the physician to pay me attention when I talk and kindle a connection between us." Once these interviewees were comfortable with their physician, they said they would freely discuss such issues as sexual matters, home problems, money matters, and religion.

### DISCUSSION

Full disclosure of health issues between Latina patients and physicians is more likely to occur in the context of a warm, trusting, compassionate relationship in which the patient feels respected and truly heard. As our study found, language barriers could create stress that worked against disclosure on both sides of the patient-physician relationship. The presence of translators sometimes added barriers to the trust and connection needed to disclose issues about which women felt embarrassed, afraid, or vulnerable. Women perceived time constraints to interfere with disclosure primarily because physicians did not hear them out, appeared uninterested in what they were saying, or were in a hurry. With respect to sex, many women stated that they were more willing to fully disclose their health issues to a female physician. Willingness to disclose was related to a lesser extent to age concordance. Sexual issues emerged as the most sensitive topic, with many interviewees, both foreign born and US born, stating that they were often not



comfortable discussing these issues and, furthermore, would not mention genital problems to avoid examination. Interviewees indicated that Latino culture, with its emphasis on relationships, was related to their wanting a warm caring connection with their physician. Even so, some US-born women tended to regard their physician more as a paid professional, the quality of whose care they should evaluate, while some foreign-born women were more likely to simply accept the physician's authority. Many foreign-born women believed that a female physician made it easier for them to disclose sexual and gynecological issues, whereas some US-born women did not express this preference so strongly.

Other studies have also reinforced that doctors' perceived lack of interest in the patient or in their particular health problem worked against disclosure. Cape and McCulloch<sup>15</sup> found that one-half of patients in general practice believed the doctor to not be interested in emotional issues and thus did not disclose them. Likewise, 94% of Latinas who never communicated about intimate partner abuse with physicians reported that their physicians did not ask about this issue,<sup>7</sup> and many believed their physicians lacked interest in this issue. An expression of interest in the form of a question was a predictor of disclosure. In women with breast cancer,<sup>3</sup> physicians' lack of inquiry was associated with women's nondisclosure of sexual orientation.<sup>3</sup>

Beach et al<sup>16</sup> found that almost double the number of patients (including Latinos) reported satisfaction with care when they were treated with dignity. For minority respondents, being treated with dignity was associated with higher adherence to physicians' advice about treatment, tests, and referrals. In our study, we did not address the topic of dignity with our participants directly. Differences between the way some foreign-born and US-born women preferred to be treated within the patient-physician relationship, however, suggest that the concept of dignity may not be uniform within Latina women. For many foreign-born women, dignity seemed to be related primarily to being heard and cared for. Some US-born women more emphasized being treated with respect—"not being belittled," as one interviewee put it.

That more than 80% of participants in this study identified problems related to language contrasts with findings from a study by Rodriguez et al, in which only about one-third of Latinas identified language barriers as a reason for not communicating important health information.<sup>7</sup> Hunt and de Voogd<sup>17</sup> reported findings similar to those in our study that the presence of English-speaking family members in prenatal counseling sessions could subvert Latina patients' ability to disclose information important to them. Other studies also emphasized the problems caused by the time constraints found in the present study.<sup>7,15</sup>

The importance of sex concordance to disclosure found in our study has been borne out in other studies as well. Disclosure of psychosocial information increases in both African American and white women, for instance, when paired with women physicians.<sup>5</sup> In a study about cancer screening,<sup>18</sup> one concern of Latino patients was nonconcordant physician sex.

Regarding culture, similar to the present study, Rodriguez et al found that women born outside the United States, most of whom were Latina, were less likely to disclose intimate partner abuse than US-born white or African American women.<sup>7</sup> Hunt and de Voogd<sup>17</sup> provided evidence that physicians' cultural stereotypes about Latinas obscured the reality of what they were saying. This issue was difficult to assess in our study's interviews of patients, but it could indirectly explain some difficulties related to disclosure. For instance, interviewees' perceptions that their physicians were not listening could be related to stereotyping, in which physicians assumed they understood the patient's context when they did not. Elderkin-Thompson et al<sup>19</sup> reported that cultural metaphors not compatible with biomedical concepts or not congruent with clinical expectations were associated with lack of communication between physician and patient.

The literature related to trust is particularly illuminating with respect to the differences we found between US- and foreign-born Latinas. In a detailed survey of patients with rheumatoid arthritis and systemic lupus erythematosus, 43% of whom were Latino and 75% of whom were female, Berrios-Rivera et al<sup>20</sup> found that the only variable significantly related to disclosure was physicians' patient-centered communication; further, Latino patients' trust in physicians was lower than that of white patients, although their trust in the US health care system was higher. Sheppard et al<sup>21</sup> conducted focus groups with mostly low-income African American women to explore experiences that influenced trust in health professionals and lay health workers. Physicians' caring, concern, and compassion were found to be important in building patient trust, as in our study. Our study, however, carries these findings further in confirming that, for Latinas, a caring and compassionate relationship is central for disclosure of important health information. Time constraints, the presence of translators, sex and age differences, and lack of awareness of what constitutes sensitive issues for Latinas can all affect this relationship and thus disclosure.

The limitations of the present study were as follows. The diversity of the sample was probably lacking in the area of sexual orientation, as none of the interviewees disclosed that they were bisexual or lesbian. The range of ages, nationalities, and other

demographic characteristics was sufficient, however, to enable study findings to be of value. These findings, for instance, could be used to inform the design of surveys, which could yield knowledge with wider generalizability. The interviews were not recorded and transcribed verbatim, limiting the selection of illustrative quotations and making less information available to researchers who did not conduct interviews. Offsetting this limitation, notes taken were rich with detail, and the interviewers were integral to data analysis and were thus able to confirm or correct interpretations.

We recommend that further research with larger samples of Latinas be done particularly on the effect of insurance status on disclosure, the relationship between the desire to preserve the family and the disclosure of STD's, and the relationships between birthplace and disclosure. Our findings uncovered possible important relationships that should be confirmed in other settings.

In conclusion, this study identified 6 factors that enhanced or inhibited Latinas' disclosure of information to their physicians. These factors could be addressed in several ways. Making sure that staff are trained in simple techniques for building rapport, such as appropriate eye contact and active listening, for instance, could help them better communicate empathy and compassion and establish trusting relationships. Reinforcing this point, many interviewees specifically requested that their clinicians hear what they said in these interviews and obtain additional training in communication. Once a sound foundation of communication is in place, maintaining continuity of care, so that the same physician sees the same patient as much as possible, would create a stronger context for honest disclosure, especially if during genital examinations the physician's and patient's sex is concordant. When translators are used, even those who are appropriate and well trained, physician awareness of the difficulty some Latinas experience disclosing sensitive information could be helpful. Under these circumstances, and when discussing any sensitive issue, particularly if related to sex, skilled communication that builds empathy and creates trust will assist Latinas to fully disclose important health information.

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**Key words:** Hispanic Americans; physician-patient relations; qualitative research; cultural competency; healthcare disparities

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