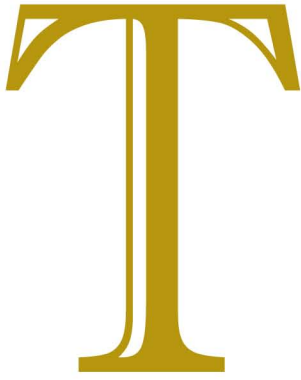


SICK AND TIRED OF BEING SICK AND TIRED

THE IMPORTANCE OF CULTURE, COMMUNICATION, AND SOCIAL SUPPORT





Teresa Diaz is 25 years old. She lives with her husband Carlos and their two children in a town near the Texas border where her husband was born. Teresa grew up in a town just over the border in Mexico.

Teresa liked and did quite well in school, but had to leave when she was 16 years old to work to help support her family. Because she lived so close to the United States border, Teresa learned enough English to communicate with the many Americans who came to her town. In the store where she worked, Teresa was promoted from the stock room to the cash register because she was able to communicate with the English speaking customers. Teresa met Carlos at a family wedding in her hometown when she was 16 years old. Teresa felt that she impressed Carlos with her ability to speak English and that she was employed and held a good position. It was “love at first sight” and soon Carlos was coming to visit the pretty and vivacious Teresa every week. Three years later, when Teresa was 19 years old, the couple was married and she moved with Carlos to his home town. Teresa and Carlos decided to begin a family right away, but they always planned that Teresa would continue her education once the kids were in school. Carlos worked as a painter during the week and sometimes found other jobs on the weekend to earn extra money. Teresa took a job cleaning office buildings at night. It worked out well because she was able to be at home during the day after the children were born and she had insurance benefits for the family. When she was 22 years old, Teresa began feeling very sick. Doctors diagnosed her with systemic lupus erythematosus (SLE).

One afternoon, three years after Mrs. Diaz has been diagnosed with SLE, she arrives for an appointment with one of her physicians, Dr. Howard

Mrs. Diaz opens the door into Dr. Howard’s office. It is a hot day and she is walking slowly. Once again Mrs. Diaz is so exhausted that she feels as if she is dragging a huge weight around as she goes through her day. She walks up to the desk and signs in. The receptionist says, “Do you realize that you are 45 minutes late. I am not sure if Dr. Howard can still see you.” Mrs. Diaz is startled. At the clinic where she receives her primary care, Mrs. Diaz is used to being told to come in the morning or afternoon and then she waits her turn. Besides, it took so long to get to Dr. Howard’s office and she is so tired. Mrs. Diaz says, “¡Hay Virgencita (Oh Dear Virgin)! No, please, I must see the doctor. My husband was supposed to drive me here, but he was called to work at the last minute. I had to take two buses to get here and the last bus was running late.”

The receptionist makes a quick phone call and says, “Ok, Dr. Howard will see you. We have some new forms that we need you to fill out. Check the last form to make sure all your information is still correct.”

Mrs. Diaz sits down nervously with the forms. She thinks to herself, “I hope I understand the questions.” She speaks and understands English well enough to get along at her job, and to do routine tasks of daily living such as shopping. Reading English is much harder for her, especially if there are complex words involved. Mrs. Diaz tries her best to understand and complete the forms, but one form describes something about privacy and another is about billing and though she is not sure what the forms say she signs them anyway. Mrs. Diaz does not want to make the receptionist angry again.

Linguistic competence in health as defined by the National Center for Cultural Competence is:

The capacity of an organization and its personnel to communicate effectively, and convey information in a manner that is easily understood by diverse groups including persons of limited English proficiency, those who have low literacy skills or are not literate, individuals with disabilities, and those who are deaf or hard of hearing. Linguistic competency requires organizational and provider capacity to respond effectively to the health and mental health literacy needs of populations served. The organization must have policy, structures, practices, procedures, and dedicated resources to support this capacity.

Goode & Jones (modified 2009). National Center for Cultural Competence, Georgetown University Center for Child & Human Development. A full definition can be found here:

<http://nccc.georgetown.edu/documents/Definition%20of%20Linguistic%20Competence.pdf>

Mrs. Diaz's difficulty with the forms she was asked to complete reflect two key aspects of linguistic competence in the health care setting. The first is *literacy* and the second is *health literacy*. Literacy and health literacy have an impact on many aspects of the health care encounter including reading and filling out forms, giving consent for treatment, understanding practice policies, or utilizing written instructions or information about treatments.

Literacy. Like many individuals whose first language is Spanish, Mrs. Diaz has difficulty reading and understanding materials in English. The National Assessment of Adult Literacy (NAAL) found that for Hispanics in America the average literacy scores for reading documents fell 14 points from 1992 to 2003. Individuals who spoke Spanish before starting school comprised only 8% of the sample for the NAAL, but comprised 35% of those who were rated below "basic" in prose literacy skills.

SOURCE: U.S. Department of Education, Institute of Education Sciences, National Center for Education Statistics. A First Look at the Literacy of America's Adults in the 21st Century.

Downloaded on 8/1/2011 from <http://nces.ed.gov/naal/pdf/2006470.pdf>

Studies show that persons with low literacy skills are less likely to:

- (1) Seek and get preventive care,
 - (2) Understand forms for informed consent,
 - (3) Understand their children's diagnosis,
 - (4) Understand medication instructions for themselves and their children, and
 - (5) Be knowledgeable about the health effects of risks, behaviors, and diseases.
- (Berkman, N., DeWalt, D. et al., 2004)

Health literacy goes beyond reading and comprehending written material. The Patient Protection and Affordable Care Acts define health literacy as "the degree to which an individual has the capacity to obtain, communicate, process, and understand health information and services in order to make appropriate health decisions." (Title V—Health Care Workforce, Subtitle A—Purpose and Definitions.)

Health literacy impacts a range of facets of healthcare, including the ability to:

- Access information
- Recognize cues to action
- Access care
- Navigate institutions
- Complete forms
- Provide consent
- Communicate with professionals
- Provide information for assessment, diagnosis & treatment
- Understand directions
- Follow regimens
- Advocate

SOURCE: Rudd, RE. (2003). Empowering Disadvantaged Populations. [Electronic Slide Presentation] Retrieved from http://www.hsph.harvard.edu/healthliteracy/overview_slides.pdf, on 7/22/05
Harvard School of Public Health, Health Literacy Studies

UPDATED SOURCE: Rudd RE. Literacy and implications for navigating health care. Harvard School of Public Health: Health Literacy Website. 2010. Available at <http://www.hsph.harvard.edu/healthliteracy/overview/>
Accessed 08/10/2013.

Issues of health literacy are further challenged by those patients who have limited English proficiency or are monolingual Spanish speakers, particularly given the lack of translated documents, bilingual staff or interpreters who can assist with reading and reviewing documents with patients. Providing quality health care includes addressing the literacy and health literacy of patients as an aspect of linguistic competence.



After about 30 minutes, a nurse comes out and calls Mrs. Diaz's name. The nurse weighs Mrs. Diaz, takes her blood pressure, and asks her about what medications she is taking. The nurse also asks Mrs. Diaz questions about how tired she is, whether she has had any fevers, noticed losing any hair, had any rashes, been short of breath, whether her joints hurt her, and many others. Mrs. Diaz listens very carefully—she is pretty sure she understands most of the questions, but when there are words she is not sure about, she just nods her head or says “no”.

Mrs. Diaz's difficulty with the complex English of the healthcare encounter also demonstrates the need for another aspect of linguistic competence in care settings—the need for language assistance services. Mrs. Diaz, like 43.1% of individuals who speak a language other than English at home, rates herself as speaking English less than “very well”.

SOURCE: U.S. Census Bureau, 2009 American Community Survey 1-year Estimates. Downloaded on 8/1/2011 from http://factfinder.census.gov/servlet/STTable?_bm=y&-geo_id=01000US&-qr_name=ACS_2009_1YR_G00_S1601&-ds_name=ACS_2009_1YR_G00_&-_lang=en&-redoLog=false&-format=&-CO NTEXT=st

Often times, in the health care setting, staff and providers assume that because they can easily converse with a patient about day to day topics in English, described in the education literature as basic interpersonal communicative skills (BICS), that the patient does not need an interpreter for health care discussions. In many instances health care encounters require cognitive academic language proficiency (CALP).

<http://www.wou.edu/~lpearso/website/Cummins.html> It may take English language learners years to develop CALP, the higher level of proficiency needed to deal with technical information, words, and concepts not part of everyday conversation, such as those typically used in health and mental health care. (Cummins, 1979) Thus, it is vital for healthcare providers and settings to make sure patients understand the information provided to or questions asked of them.

As such, service providers should implement policies and procedures to provide access to services and information in appropriate languages other than English to ensure that persons with limited English proficiency are effectively informed and effectively participate in any benefit. For Mrs. Diaz, access to a trained medical interpreter would have assured that she understood the questions asked and that Dr. Howard had accurate information to provide her with quality care. *See Title VI, Section 601 of the Civil Rights Act of 1964* <http://www.lep.gov/> (requires that services provided through Medicare and Medicaid provide access to those services, and information, in appropriate languages other than English).

A large, stylized, gold-colored letter 'S' that serves as a decorative element for the start of the narrative text.

Soon Mrs. Diaz is sitting in the examining room waiting for Dr. Howard. He is friendly and upbeat. He comes in and greets her with a big smile. “So, how have things been going?”

Mrs. Diaz sighs and says, “¡Ay Doctor Howard (Oh, Doctor Howard), I am not feeling very well these days!”

Dr. Howard looks through her chart. He asks Mrs. Diaz again about her medications, her appetite, about any pain. Then Dr. Howard pulls out a piece of paper with her latest laboratory results. He says, “Mrs. Diaz, to me it looks like you are doing well. Your lab results are stable and a few have actually improved since you last came to see me.”

“Pero (But) Dr. Howard, I feel so bad all the time. I am so tired.”

Studies report that discordance between physician and patient ratings of disease activity may affect quality of care. Patients tend to be more concerned about how they feel, while physicians tend to focus on objective signs, particularly laboratory test results. The difference in Mrs. Diaz’s perception of how well she is doing and Dr. Howard’s view of her health status can interfere with the treatment process. First, Mrs. Diaz may come to believe that Dr. Howard is yet another person in her life who does not believe that she is struggling with her disease. Second, Mrs. Diaz may want medical treatments beyond what Dr. Howard thinks are necessary. (Pons-Estel, Alarcon, Scofield, Reinlib, & Cooper, 2010)

S “Some fatigue is expected, but based on everything I see you should be proud of yourself. It looks like you are taking all of your medicines regularly. Is that right?”

Mrs. Diaz nods and says, “yes, I really try to, doctor.”

S “I have explained to you before about how the medicines work. But it can’t hurt to go over it again.” Dr. Howard explains her treatment. Mrs. Diaz finds it hard to follow. She thinks to herself, “¡ Ay Señor (Oh God)! Dr. Howard speaks so quickly and uses a lot of English words that I do not really know. Maybe it’s best if I just nod.” She knows the doctor is very busy and cannot take time to explain the words to her. She believes it is not Dr. Howard’s fault that she does not know English well.

Dr. Howard says, “Here is something to read about lupus, that may help you understand the disease better.” Mrs. Diaz takes the pamphlets. She notices that they are in English and Spanish. She is grateful that they are in Spanish too, but even the Spanish explanations seem complicated. Mrs. Diaz wishes someone could just talk to her about what is in the pamphlet.

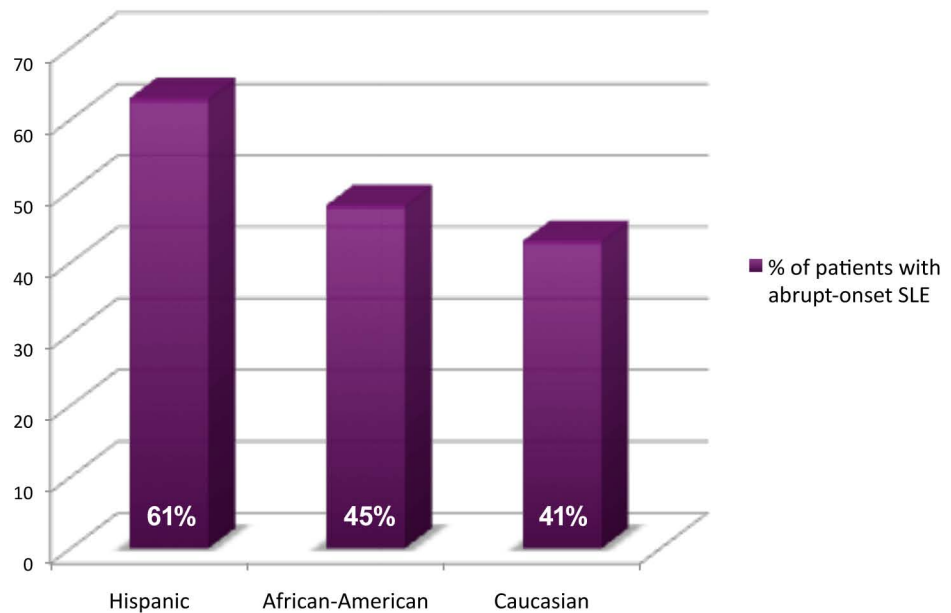
Patients may prefer to get health information in different formats. As noted in the definition of linguistic competence, the goal is effective communication of important information that patients need to address their health. Thus health information should be provided not only in the language patients prefer, but also at literacy and health literacy levels they can understand, using plain language <http://www.nih.gov/clearcommunication/plainlanguage.htm> and in a format that maximizes their learning.

A As Dr. Howard gets up to leave, Mrs. Diaz begins to cry. “Dr. Howard, I feel very alone. No one understands that I am sick. On days that I feel really bad, it is hard to work, come home and take care of the kids, and get dinner on the table. There is no one who helps me—sometimes no one seems to believe I am really sick. The lady I work for will ask, ‘Do you have a fever, are you throwing up?’ and if I say no, then she says, then you aren’t really sick. She says she is tired of my excuses. I try not to complain. I continue to push myself even when I am feeling poorly because I am afraid I will lose my job, and I need my job! There is no one who can help me with the kids when I feel bad. This lupus thing is so hard. I was always a very healthy child. Then suddenly after I got married, I got so sick. It seems like overnight I started doing very badly. My husband is good about it, but sometimes I think he feels like he got tricked—I was healthy and strong and now I am always sick.”

Hispanic patients with SLE in the LUMINA study were reported to be significantly more likely to have abrupt onset of their disease. Figure 1 illustrates the differences in abrupt onset among Hispanic, African American and Caucasian patients. (Alarcon et al., 1999)

Figure 1

Comparison of Abrupt-Onset SLE by Race/Ethnicity
Sample from LUMINA Study (Alarcon, et.al., 1999)



Patient group comprised of 229 participants from three ethnic groups. (70 Hispanic, 88 African-American, 71 Caucasian)



“Dr. Howard, my husband works two jobs. I was so happy when my sister moved here, I thought she could help. But she is busy with work and is pregnant now and cannot really help me. I think that no one understands that I am sick—they think I am lazy and a big complainer. And then I have to take time for all the doctor appointments. I am sorry I was late today—I had to take two buses. We cannot afford two cars and no one I know could give me a ride.”

Mrs. Diaz’ concerns about needing people in her life to help her are, actually, a key factor in the course and treatment of her SLE. Asking about an SLE patient’s supportive network and addressing any concerns about feeling alone or having no help is an important component of treatment. Addressing these issues with Hispanic patients may be particularly important. A number of research studies have reported the following:

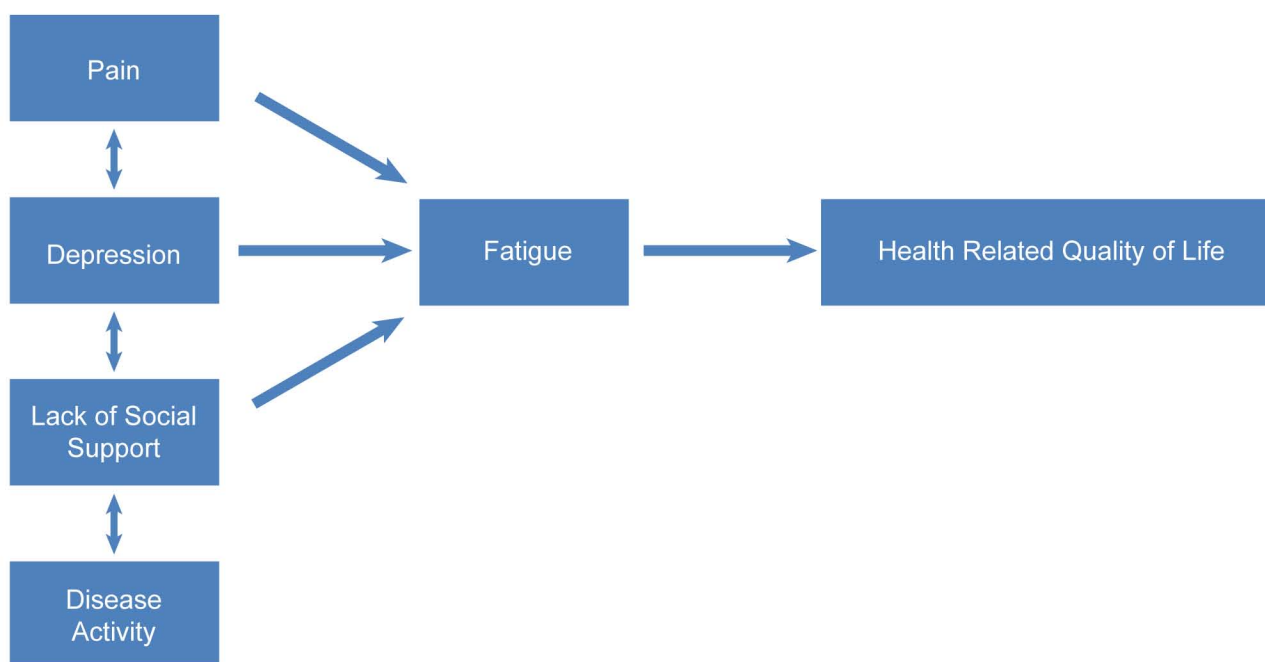
- Social support (having people in one’s life that can provide tangible and emotional help) plays a critical role in the health and well-being of individuals with SLE.(Karlson et al., 1997; Sanchez et al., 2009);
- Poor social support has been found to be associated with higher levels of disease activity, as well as subjective health related quality of life for SLE patients;
- And over the course of the disease, demographic, behavioral and psychological variables, including Hispanic ethnicity (sample population from Texas) and social support are important mediators of disease, while genetic factors do not influence disease activity over time. (Alarcon et al., 2006).

Several studies have reported that Hispanics with SLE have significantly lower levels of reported social support than Caucasians. (Alarcon et al., 2006) One study has demonstrated that an intervention with spouses or other family members and individuals with SLE decreased their reported fatigue—one of Mrs. Diaz main complaints. (Karlson et al., 2004) Mrs. Diaz needs more than Dr. Howard's sympathy for her concerns --addressing her lack of social support needs to be an integral part of her treatment.

Mrs. Diaz, like many SLE patients, struggles with fatigue. It is her main complaint. Yet Dr. Howard sees that her lab results are not raising any red flags. Studies report that disease activity is not a significant predictor of fatigue scores. Social support is a significant predictor. In addition, in a multivariate analysis pain, depression and perceived social support account for close to half of the variance of perceived levels of fatigue in the study sample. (Jump, 2005) This triad—lack of social support, depression and pain—become important points to assess and address for SLE patients, particularly those reporting fatigue as a major obstacle to quality of life. Figure 2 illustrates this complex set of interrelationships. Identifying and addressing depression in individuals is challenging for physicians when the chief complaints are somatic. In addition, studies report that Hispanics with depression are significantly less likely to be diagnosed and appropriately treated for depression than non-Hispanic whites. (Lewis-Fernandez, Das, Alfonso, Weissman, & Olfson, 2005; Simpson, Krishnan, Kunik, & Ruiz, 2007) So Dr. Howard needs to look beyond the medical variables to address Mrs. Diaz's main concern. Assessment for possible depression and then appropriate treatment, ongoing assessment of pain and addressing her lack of social support all become part of the treatment approach.

Figure 2

Relationships Among Pain, Depression, Lack of Social Support, Disease Activity and Health Related Quality of Life





Dr. Howard is very concerned. He pats Mrs. Diaz's hand and he realizes that Mrs. Diaz's life experiences are impacting her health. But what can he do?

A guiding principle of cultural competence involves working in conjunction with natural, informal support and helping networks within culturally diverse communities. Provider knowledge of and connection to both informal and formal systems of support are necessary to be responsive to unique needs of culturally and linguistically diverse patient populations, including those with SLE. As seen with Mrs. Diaz, culture impacts the type, scope, intensity,

and duration of social supports. Such cultural factors include age, gender, marital status, family role, socio-economic status, religious affiliation or spirituality, and importantly health beliefs and practices. As so poignantly described, Mrs. Diaz has a number of social support needs that many providers may view as extending well beyond the boundaries of their clinical practice. Dr. Howard is not expected to solve the problems Mrs. Diaz is experiencing in her day to day responsibilities as a working mother and wife. However Dr. Howard, as well as other providers, can indeed play an important role by having knowledge of the manifestation of SLE in Latino patients across the life cycle, using history taking approaches to elicit health, mental health, and social concerns that take into account cultural contexts, and knowing where to refer for supportive services that are culturally and linguistically competent. Below find selected examples of providing social supports that may be appropriate for Mrs. Diaz.

- *Convene a family meeting.* Ask for a time to meet with Mr. & Mrs. Diaz and any other family members or friends that the couple believes should have information about SLE in general, and the impact on Mrs. Diaz in particular. To the extent possible, offer times that do not interfere with the couple's work schedule. Provide information in "plain talk" and use bilingual staff or a qualified Spanish language interpreter if this is the family's preferred way of receiving information. Help to dispel the notion that Mrs. Diaz is simply lazy and address the types of supports she may need.
- *Draw upon faith beliefs and religious affiliations.* Explore with Mrs. Diaz her faith beliefs, religious affiliations and practices and the extent to which they are helpful to address concerns about her illness. Explore whether Mrs. Diaz is comfortable seeking supportive services from the faith community (e.g. family counseling, child care, prayer or meditation groups, parish nursing, transportation, meal share programs).
- *Discover world view and belief systems about mental health.* There is a negative stigma associated with mental illness and seeking mental health services among many within Latino communities. Gently discover Mrs. Diaz's belief systems to determine if she is open to counseling and other supports. Refer to those providers who have experience and language capacity for Spanish-speaking patient populations. Also consider, SLE support groups focused on prevention and social-emotional support.
- *La familia puede ayuda (The family can help).* Encourage Mr. & Mrs. Diaz to discover what family members, including extended relatives, are willing to help on days when Mrs. Diaz is feeling badly (e.g. meals, child care, brief respite, transportation).
- *Address employer discrimination.* Identify resources that address employer discrimination related to SLE and other health conditions. Disseminate written materials and contact information for patients who prefer to meet or speak with staff about their concerns.

The world view of many cultural groups integrate physical, emotional, and spiritual well-being, and hold that all three are necessary for optimum health. Providers' acceptance of these world views and willingness to integrate social support strategies in their practice models are consistent with principles of best practices of cultural and linguistic competence.

Questions for Reflection

1. How could this clinical encounter have been handled differently?
2. How can the issues raised by this vignette be addressed in your practice/organization?
 - Literacy
 - Health literacy
3. What are the policies within your practice/organization on the provision of language access services?
4. How do you and others in your practice/organization keep abreast of current research on racially and ethnically diverse patient populations, including those with SLE? How does this inform your practice?

Resources

Resources on addressing language access services, health literacy and patient/provider communication:

National Center for Cultural Competence has a web feature on FAQs about language access. <http://www11.georgetown.edu/research/gucchd/nccc/features/language.html>

Let Everyone Participate, a website from the Federal government has resources and information on meaningful access for people who have limited English proficiency. This is a good one-stop spot for the latest policies and guidelines from the Federal government. This site also offers opportunities for technical assistance, information and help with specific questions. It also has demographic information and links. See <http://www.lep.gov/>

Small health care practices are challenged in providing the kinds of language services required by Title VI of the Civil Rights Act of 1964. The Commonwealth Fund has published a report on Providing Language Services in Small Health Care Provider Settings: Examples from the Field (Yodelman and Perkins, 2005). http://www.commonwealthfund.org/usr_doc/810_Youdelman_providing_language_services.pdf

The Health Resources and Services Administration (HRSA) offers on-line CME courses on these topics at <http://www.hrsa.gov/publichealth/healthliteracy/index.html> *Unified Health Communication (UHC): Addressing Health Literacy, Cultural Competency, and Limited English Proficiency* is free, on-line, go-at-your-own-pace training that has helped more than 4,000 health care professionals and students improve patient-provider communication.

National Council of La Raza has a series of profiles of Latino health. There is useful information in the section on "Question 10. How does patient provider communication affect the quality of Latino's health care." <http://www.nclr.org/images/uploads/pages/Question10.pdf>

Health Care Language Services Implementation Guide has been developed by the U.S. Department of Health and Human Services to provide information to health care settings. <https://hclsig.thinkculturalhealth.hhs.gov/>

The Clear Communication website of the National Institutes for Health provides information about using Plain Language as a way to make health information understandable and useful for all patients. <http://www.nih.gov/clearcommunication/plainlanguage.htm>

The simple and effective "Teach Back" method of improving communication related to health literacy in the patient encounter is explained in a power point from the National Center for Health Literacy. www.nchealthliteracy.org/toolkit/tool5A.ppt

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