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Palliative Care for Latino Patients and Their Families: “Whenever We Prayed, She Wept”

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Abstract

Latinos account for 15% of the US population, a proportion projected to grow to 30% by the year 2050. Although there is tremendous diversity within this community, commonalities of language, beliefs, attitudes, and behaviors unite Latinos, making them more similar than different. For non-Latino and non-Spanish-speaking clinicians, communication barriers and cultural misunderstandings can impede the care of dying Latino patients and their families. We present the case of a young, pregnant, Spanish-speaking woman from Guatemala diagnosed with a fatal leukemia. As illustrated by this case, Latino immigrants face a number of external challenges to optimal end-of-life care: (1) geographic distance as well as political and economic realities often separate patients from their valued families; (2) undocumented immigrants are frequently uninsured, and fear of deportation may create a barrier to accessing health services; (3) language and literacy barriers; and (4) concerns about discrimination. Other Latino issues that may be more pronounced in end-of-life settings include cultural themes and religious and spiritual influences. We recommend that professional interpreters must be used for discussions about goals of care with Spanish-speaking patients and families, or when negotiating conflict between the patient, family, and the health care team. Concrete suggestions are provided for clinicians in working with interpreters, eliciting culturally-based attitudes and beliefs, and implementing universal strategies for clear health communication.

The Patient's Story

Ms C, a 22-year-old woman from Guatemala who spoke only Spanish, initially presented in December 2006, during her 34th week of pregnancy, with marked leukocytosis and was diagnosed with acute myelogenous leukemia (AML). After delivering a healthy full-term daughter, she achieved remission with chemotherapy. However, 6 months later, a repeat bone marrow biopsy revealed relapsed AML. Ms C was transferred to a university hospital in June 2007 where she was treated with a second round of chemotherapy. In July, a bone marrow

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biopsy showed persistent AML. In discussions with Ms C and her partner, Mr M (the baby's father), the attending oncologist stated that there were no further curative treatment options.

Ms C was the oldest of many siblings, all of whom lived in rural Guatemala. Prior to her hospitalization, the patient lived with her 8-month-old daughter, Mr M, and his family. Ms C and Mr M were evangelical Christians and were undocumented immigrants. Mr M worked as a delivery person from 4 AM to 1 PM, then took over childcare duties while Ms C worked as a cook. Ms C was often deferential to her partner, allowing him to make medical decisions for her, although she had not officially designated him (or anyone else) as her health care proxy. Despite intensive efforts by the hospital social workers, it was not possible to obtain emergency visas for family in Guatemala to visit Ms C.

On July 30, 2007, after private conversations with the oncology team, the patient agreed to a "DNR/DNI" order. At the time of the Palliative Care Service (PCS) consultation on July 31, 2007, the patient had been in respiratory distress for several days but was still able to discuss goals of care and make medical decisions. Discussion with the PCS in Spanish clarified that Ms C's primary goal was to spend as much time as possible with her daughter in her remaining weeks, which would not be feasible were she transferred to the ICU. Mr M, however, requested that "everything be done," saying, "we continue to hope and pray for a miracle." In subsequent meetings, the PCS consultants reinforced the oncologist's assessment that curative options had been exhausted and encouraged her partner to begin his goodbyes. The PCS team was less and less able to engage Ms C in discussions due to somnolence, and Mr M wished only to discuss further curative treatment options and declined to consider discussions about end-of-life care plans. Mr M adamantly maintained that there was still hope for her recovery and continued to inquire about therapeutic options such as "surgery for her lungs" and "washing her blood."

Despite supplemental oxygen and escalating doses of morphine and lorazepam, the patient's dyspnea worsened. On August 6, 2007, at 2:15 AM, a nurse noted that the patient had stopped breathing. When the oncology team arrived to pronounce her dead, they found Mr M trying to revive her by performing mouth-to-mouth resuscitation.

The palliative care attending, the medical student, the social worker, and the chaplain were interviewed by a Perspectives editor in January, 2008, 5 months after the patient's death.

Perspectives

Palliative Care Attending

This was an incredibly difficult case. When we first went to see this patient ...it was clear that she was profoundly dyspneic and uncomfortable. She only spoke Spanish and I don't speak Spanish. We were lucky enough to have a resident who was Latino, so he and the medical student, who also spoke Spanish, translated. The first thing that we tried to address was her dyspnea... Her husband was very concerned that she would not be able to talk to him [if she were treated with opioids]. He really believed that she would get better and there was very little opening to even consider that she wouldn't get better. There were no holes that I could find to even bring it up.

Medical Student

He was adamantly maintaining that a miracle was possible and that anything could happen - this contributed to his inability to accept what the DNR/DNI meant.

Social Worker

He was very suspicious of any questions about her [immigration] status. He felt that we were asking questions that were inappropriate because he was really only interested in treatment options. If we asked anything that wasn't directly addressing those, he would question why we were asking.

Chaplain

In my own personal notes about this case, I had written that this was a tragic case.... I remember her infant daughter lying on the bed with her. It was a very stark image. My notes read, "Whenever we prayed, she wept."

Overview

A young pregnant woman develops a fatal cancer, and dies before her daughter reaches her first birthday. Her partner cannot bear the thought of her dying. The suffering experienced by this patient, her partner, and the health care team, suffuses all of the care providers' descriptions of this case. The deep sadness here is universal.

What is also clear is the profound influence of culture and immigration on this young woman's experience at the end of life, and that of her partner. Below we discuss ways in which Latino culture can influence the experience of terminal illness. Unfortunately, research directed at understanding and improving end-of-life care in the Latino community is relatively limited. Most studies of racial/ethnic difference in end-of-life care have focused on differences between African Americans and whites, and studies that include Latinos are often underpowered to find differences.¹⁻³ Despite these limitations, we cite the best available evidence, sharing our own experiences and suggestions where data do not exist.

Available evidence about rates of advance care planning in the Latino community is mixed. Rates of hospice use among Latinos appear to be similar to whites. In a recent multi-center study of patients with advanced cancer, only 47% (29/62) of Latino patients versus 80% (249/312) of white patients had an advance care plan.⁴ However, in a study of 239 elderly white and 224 elderly Latino subjects in New York City, only 35% had completed a health care proxy and rates did not differ by ethnicity.⁵ A third study of 40,930 elderly patients with advanced cancer found that Latinos had slightly lower rates of hospice use compared with whites (38% vs 42%).⁶

We first describe the diversity within the Latino community and discuss the influence of the immigrant experience, and then focus on communication issues including language discordance, use of interpreters, and health literacy. Next, we discuss Latino cultural norms and beliefs that may influence end-of-life decision-making, appreciating the importance of religion and spirituality, and exploring experiences of discrimination. Finally, we provide concrete suggestions to assist clinicians in using interpreters, fostering clear health communication, promoting trustworthiness, and understanding cultural interpretations of illness. Our goal is to educate clinicians of every specialty to improve culturally competent care of seriously ill Latinos and their families.

Appreciating Diversity and Commonality within the Latino Community

Chaplain—I don't think that there's any question that we could have done a better job [from a cultural perspective]... We're talking about foundational beliefs and about comfort – not the medical comfort, but comfort with the space, the presence, the people. Think about if we were receiving our end-of-life care in [Latin America], surrounded by Spanish-speaking people...

Latinos are the largest ethnic minority group in the US, currently accounting for 15% of the US population, a proportion that is projected to grow to 30% by the year 2050.⁷ Latin American culture is diverse and influenced by national origin and social class. Latin America today is a product of 500 years of population and cultural admixture of the indigenous peoples, the European colonialists and immigrants, and the forced migration of Africans.⁸ Within the Latino community in the US, there is considerable variation in health care access and utilization patterns by country of origin, English language proficiency, insurance status, and length of time in the US, emphasizing the heterogeneity of the population, much like any other racial or ethnic group.⁹ However, the predominant use of the Spanish language and shared cultural themes create definite similarities among Latinos in the US.¹⁰ Clinically, making assumptions about individuals based on ethnic and cultural identity risks stereotyping. However, ignoring the profound influence of culture and social situation on patients' experiences of illness, expectations of medical interventions, communication styles, and ways of coping can lead to misunderstanding, conflict, anger, resentment, and lower quality care.^{1, 11}

Immigrant Experience and the End of Life

Chaplain—They seemed fairly isolated. I don't recall anybody other than the partner being present when I was there...I know that there was a lot of distress about the future for this baby. The patient and her partner weren't married. I'm not sure about their immigration status... I would assume that there were a lot of fears in play around that. ...

For many Latinos in the US, the experience of illness is influenced by their experience as immigrants. Over 50% of immigrants to the US are from Latin America, and of the Latinos in the US, 40% were born in Latin America.¹² In 2000, there were 16 million immigrants to the US from Latin America: 11 million from Central America and Mexico, 3 million from the Caribbean, and 2 million from South America.¹² According to the Pew Hispanic Center, 57% of undocumented immigrants to the US are from Mexico, and 24% from elsewhere in Latin American.¹³ Research on the experiences of undocumented Latinos is limited and is challenged by difficulties identifying and sampling participants due to fear of deportation.¹⁴

Fear of deportation likely contributed to conflict between the PCS and Mr M. Deportation is a constant reality for undocumented Latinos that often precludes access to health care and may lead to negative perceptions of the health care environment.¹⁴⁻¹⁶ Recent, well-publicized cases of "hospital deportation" may further exacerbate fears among undocumented immigrants.¹⁷ Rates of uninsurance are high among undocumented immigrants (59% in 2004 according to a recent report by the Urban Institute).¹⁸ The Federal Personal Responsibility and Work Opportunity Reconciliation (Welfare Reform) Act of 1996 limits federal funding for health services for undocumented immigrants to emergency services (under Medicaid).¹⁹ The degree of support for non-emergency services is limited and varies by state. Although government agencies are required to verify immigration status in determining Medicaid eligibility, health care providers, including social workers and interpreters, are not legally mandated to report undocumented immigrants to US Citizenship and Immigration Services (USCIS, formerly the INS).²⁰ Because all immigrants are eligible for non-federally funded health benefits, hospitals and health care workers should not attempt to verify patient's citizenship status as a routine practice for providing care. Proposition 187, a voter-approved California ballot initiative later overturned in the courts, would have mandated that health care providers report undocumented immigrants to immigration authorities.²¹

From the patient's perspective, inquiring about immigration status should only be done when the benefits outweigh the risks, and in this case, could have caused a fear of deportation, a sense of discrimination, diminished trust, and worsening communication barriers. However, awareness of immigration status could have been used in planning for future care of the baby, might have helped bring into the open Mr M's distrust and the fears, and would have directly

addressed Mr M's perception that curative care was being withheld due to their undocumented status. In cases such as this, clinicians might assume that the patient is undocumented unless the patient volunteers information otherwise. Social workers may be best-positioned to ask about immigration status, so as to separate clinical care from the immigration issue. In this case, a social worker discovered that both the patient and her partner were undocumented immigrants, but this information was not communicated to the PCS teams. If clinicians do choose to ask, they might begin by stating, "I want to ask you about your immigration status. I am not asking for legal reasons and anything you say will not be reported by me or other care providers to the immigration authorities. I ask because I care about you and worry that you might have fears or concerns about how your immigration status is impacting the care you (or your loved one) are receiving." Involving local legal and social support groups and seeking out more information resources may have helped illuminate issues concerning custody of the child and educating the medical team about relevant cultural issues (see Web Resources).²²

Communication Issues

Language barriers

Medical Student—[The partner's] English was better [than the patient's]. We could kind of talk in "Spanglish." ... I think we could have done better [in terms of cultural sensitivity]. For instance, I think we could have used a professional translator all the time.

Thirty-two million of the estimated 44 million Latinos residing in the US speak Spanish at home.²³ English proficiency varies by generational status; in a recent Pew Hispanic Center study of 14,057 Latino adults, 23% of immigrant first generation Latinos reported being able to speak English very well, compared with 88% among the second generation, and 94% among later generations.²⁴ Errors in understanding are common when clinicians attempt to communicate in English with Spanish-speaking patients with limited English proficiency (LEP).²⁵ Even when Latinos do not understand, they may signal understanding to appear cooperative and not defy the authority figure.²⁶⁻²⁸

The number of Spanish-speaking health professionals is growing, and some evidence suggests that Spanish-speaking patients give higher ratings of care to Spanish-speaking clinicians.²⁹ However, health professionals' level of fluency in Spanish varies greatly. Language fluency is not a yes/no skill but a spectrum that includes facility of language, familiarity with medical terminology, and understanding of cultural context. An imbalance between speaking ability and understanding may lead to situations in which clinicians can ask simple questions in Spanish, but not understand complex responses.³¹ Using *ad hoc* interpreters, such as bilingual staff or adult family members, may be expedient, but is also potentially problematic. In a recent qualitative study, professional interpreters made fewer significant errors compared with *ad hoc* interpreters (53% versus 77%, $p < .0001$).³² In addition to important errors, clinicians may be concerned that *ad hoc* interpreters, particularly family members, may alter the interpreted content to suit their own beliefs or otherwise affect the patient's responses. Title VI of the 1964 Civil Rights Act provides the basis for a legal right to an interpreter, a principle reinforced by the courts and President Clinton's Executive Order 13,166.³³ Unfortunately, many LEP patients are unaware of their legal right to a trained medical interpreter.³³ Thus, Latino patients should be informed about their legal right to an interpreter at no cost, and offered one if desired.³¹ Health care providers do not need to obtain informed consent from patients prior to disclosing protected health information to interpreters.³⁴

Although not realistic that all LEP patient encounters be facilitated by a professional interpreter, there are particularly sensitive, complicated, or important conversations during which professional interpretation should be mandatory. These include conversations about goals and preferences for care at the end of life or, as in this case, situations with significant conflict

between the patient, caregiver, and health care team. Physician training in the use of interpreters is advised,³⁵ and when used, clinicians should follow established recommendations (see Table 1).³⁶ In a recent national survey, 68% of US hospitals reported trained interpreters on staff, and 92% reported that telephone interpretation services were available.³⁷ In hospitals without professional interpreter services, telephone interpretation services can be critical for communication (see Web Resources). Videoconferencing technology may also be available. In pressing clinical scenarios, use of dual telephones with a professional interpreter intermediary can facilitate rapid communication. With Ms C and Mr M, the clinicians should have used professional interpreters for all key interactions and telephone interpreters when staff interpreters were unavailable.

Yet even professional interpretation has important limitations in the context of complex end-of-life decision making. Two studies demonstrated that interpreter-led family meetings in the ICU, when compared with meetings that did not require an interpreter, were 6 minutes shorter, contained fewer supportive statements, and commonly included interpretation errors.^{38, 39} Further, language fluency and cultural competence are not the same. Although an interpreter may be fluent in Spanish, she or he may not understand the cultural context of a patient's country of origin. Consequently, clinicians need to be vigilant in checking for understanding and exploring patient and family members' cultural understanding of illness (see Boxes 1 and 2). Patient navigators, who are trained advocates from within the Latino community, may facilitate culturally competent communication, helping seriously ill patients navigate the health care system, and identifying barriers to optimum palliative care.⁴⁰ Evidence for the effectiveness of patient navigators has not been evaluated in end-of-life settings.

Health Literacy Considerations

Medical Student—To be frank, I'm not quite sure [about reasons for the partner's misunderstanding of the DNR/DNI status]. It was probably partly his health literacy.

Health literacy has been defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.”⁴¹ Close to half of the US population has limited health literacy;⁴² however, the prevalence of limited health literacy is higher among Spanish-speakers (62%) compared with English-speakers (46%).⁴³ In addition, health literacy is tightly linked to educational attainment and reading skill, all 3 of which are the lowest among Latinos, as compared with all other US race/ethnic groups.^{42, 44} Notably, health literacy is a dynamic construct that is influenced by the demands and expectations placed on a patient by the health care system, the nature of the patient's disease process, emotional stresses, and prior experiences with medical decision making.^{45, 46} Patients with limited health literacy are more likely to have difficulty processing written and oral health information⁴⁷⁻⁴⁹ and to have difficulty navigating the health care environment,^{41, 50-52} and are less likely to engage in shared decision-making or to report that interactions with clinicians are helpful or empowering.^{51, 53, 54}

Optimal communication techniques include assessing prior knowledge, using simple language without jargon, encouraging questions, and using the “teach back” method (Box 1).⁵⁵ Employing proper communication techniques may be one of the most important interventions to reduce health disparities related to limited health literacy.⁵⁶⁻⁵⁸ Due to issues of shame and potential stigma, it is recommended that clinicians adopt clear health communication techniques for all patients rather than screening for or measuring patients' health literacy.⁵⁹

Cultural Considerations in Care at the Close of Life for Latino Patients

Palliative Care Attending—I only had a few minutes alone with her when her husband wasn't there... I got very different concerns from her than I got from him, and that definitely

impeded her care. She really wanted her symptoms controlled and wanted to talk about her baby. She was desperate to see her parents. He would always focus back on the medical issues, so we weren't able to address her concerns. It was very frustrating and very hard.

Medical Student—I think [there was a sense of fatalism on the part of the patient], in the sense of her resignation, particularly in regard to her daughter.

Appreciating the influence of cultural expectations of care and acculturation is critically important.⁶⁰ In Latin America, physicians often do not disclose bad news or poor prognosis with their patients and are expected to keep up the patients' hope.⁶¹⁻⁶³ In a recent study of 91 advanced cancer patients in Cuba, for example, only 41% knew that they had cancer, and patients who knew their diagnosis reported less anxiety compared to patients who did not know.⁶³ However, in a US survey, not informing the patient of a poor-outcome fatal disease was preferred by about a third of older Mexican Americans, as compared with less than 15% of whites or African Americans.⁶⁴ Evidence suggests that Latinos expect physicians to take a more directive role with regard to decisions regarding life-sustaining treatment.^{65, 66} Further, although growing, access to palliative care programs and to liberal use of opioids are limited in Latin America, particularly in resource-poor nations such as Guatemala. Efforts aimed at increasing opioid availability face significant challenges, including high costs of commercial opioid preparations, bureaucratic requirements, restrictive legislation, and lack of physician education.^{67, 68} Clinicians should attempt to bridge such gaps stemming from cultural perspectives and expectations (Box 2).

Regardless of country of origin or degree of acculturation in the US, a number of culturally-based beliefs and attitudes that permeate the Latino community may influence illness experience, decision-making, and care at the end of life. These “cultural scripts” (culturally based patterns of social interaction) include *familismo*, *machismo*, and *fatalismo*.^{10, 26} Although these cultural scripts present themselves in many clinical situations, they may be particularly prominent at the end of life (Table 2). Clinicians should note that these cultural scripts may exist and operate to a greater or lesser extent in many Latinos, but there is marked individual variation, particularly according to social class and acculturation.^{60, 69} Conversely, although clinicians should be attuned to these cultural scripts (cultural “sensitivity”), they should refrain from stereotyping and assuming that these scripts are applicable to all Latino patients. A broad approach may be a useful starting point (Box 2).

Familismo: Latinos place great value on the family, which may include not only the nuclear family but also godparents, family friends, neighbors, distant relatives, and even a former spouse.^{27, 70} The extended family forms a collective support network with strong ties of solidarity, interdependence, and loyalty. Clinicians should be prepared for large families to be present at the bedside and to be involved in care. Clinical decision-making needs to be considered in the collective context of the family unit; this runs counter to the individual-based paradigm in US mainstream culture. In this case, the family unit was Ms C and Mr M (Ms C's partner and father of their baby) and the clinicians might have managed the patient's care with this in mind. In addition, Ms C desperately wanted support from her parents in Guatemala in her last month of life. For some Latinos, particularly recent immigrants such as Ms C, family involvement in medical decision-making may be hindered by immigration status, vast geographical distance, and serious political and economic constraints. Despite the best efforts of the medical team, the rapidity of Ms C's decline and the political reality that made it nearly impossible to obtain visas, her family could not be with her at the time of death. In retrospect, clinicians in this case may have missed opportunities to transport her to Guatemala to be with her family before she became unstable, and could perhaps have contacted Ms C's family there by phone to assist with decision making. If a patient's loved ones have access to the Internet and a webcam, patients may be able to see, as well as talk to, loved ones. In addition, Latino

community organizations or the patient's church may be able to provide volunteers to act as support in the family's stead.

Machismo: Traditional gender roles are maintained in much of Latin America, particularly among those of less privileged social classes.^{26, 69, 71} And despite a strong male predominance in society, women are more often responsible for health issues in a family. Although *machismo* is a term with negative connotations of male oppression, it also refers to the need men feel to serve as the family provider and protector. *Machismo* can have an overwhelming influence on decision-making for Latina women, when male family members assert their caring by making most of the decisions.^{71, 72} In order to truly assess Latina patients' goals and desires for care, clinicians may need to elicit their concerns and preferences in private, if this is acceptable to the patient. In this case, Ms C was seriously ill, profoundly dyspneic, and did not speak English. The extent to which Ms C's deference to Mr M resulted from *machismo* or powerlessness due to her medical condition, or other social or religious factors, is unknown. Latino male patients, on the other hand, may feel shame and disappointment when symptoms or functional decline limit their ability to fulfill patriarchal expectations.¹⁵ Clinicians should respectfully inquire about these concerns, and consider creative ways of helping Latinos contribute to their family at the end of life. For example, doctors may describe their recommended treatments as a way to provide for the family by saying, "These medications will help you be as pain free as possible, so you can continue to care for your family."

Fatalismo: *Fatalismo*, or fatalism, is a belief in fate -- that one's future is pre-ordained or not under one's control. *Fatalismo* has been primarily studied as beliefs and attitudes about cancer that may deter Latinos from participating in cancer screening and other preventive services.^{73, 74} *Fatalismo* probably played a limited role in this particular case, especially for Mr M, but when patients are seriously or terminally ill, *fatalismo* may manifest as pessimistic attitudes about the future, leading patients to delay seeking treatment and potentially to suffer alone.^{75, 76} Whether *fatalismo* contributes as an independent factor to health-related behavior is currently unknown. *Fatalismo* may also be confused with the spirituality of devoutly religious persons.^{77, 78}

Religious and Spiritual Considerations

Chaplain—On the intake form, where they ask for religion, somebody had put in "Catholic"... But it became clear from the family that they were not Catholic... They were evangelical Christians.

Religion and spirituality (*la espiritualidad*) have a powerful influence on many Latinos. According to a recent Pew study of 4,016 Latinos, 92% consider themselves religious -- 68% are Roman Catholic and 15%, Evangelical or "born-again" Protestants (*Evangelistas*).⁷⁹ Evangelicals pray more, attend religious services more frequently, and evangelize more frequently than Catholics, and are more likely to believe the Bible to be literally true.⁷⁹ The incorrect categorization of Ms C's religious affiliation highlights the need to specifically ask patients about their religion and to refrain from stereotyping.

Mr M made clear to multiple members of the medical team that he did not want to engage in discussions not focused on curative treatment, stating that he was hoping for a "miracle." Interviews reveal the team's frustration, as they felt unable to discuss issues identified as important by Ms C, particularly planning for care for the baby after her death. The extent to which Mr M's belief in miracles represented a religious belief as opposed to an expression of denial or frustration at his loss of control is unclear.⁸⁰

Many religious and spiritual considerations apply similarly across cultures.⁸⁰ In a recent study of a diverse group of patients with advanced cancer, religiousness was associated with wanting

all measures to extend life, even after adjustment for race and ethnicity (odds ratio, 1.96; 95% CI, 1.08 to 3.57).⁸¹ In focus groups, Latino surrogates indicated that suffering was to be borne as part of a test of faith.⁸² This concept has also been noted frequently in literature on attitudes of African Americans toward end-of-life care as well, and may represent a common expression of perseverance and struggle in the face of discrimination and subjugation.⁸³⁻⁸⁵ Also striking is the degree to which death is acknowledged and even celebrated in some Latino cultures, such as *El Dia de los Muertos* (Day of the Dead) in Mexico. This ancestral holiday is focused on honoring and celebrating the dead and the coming together of family when there is a death.¹⁰ Clinician exploration of these beliefs may start with the simple question, “Can you tell me about religious or spiritual beliefs or practices that are important to you?” When patients agree, involving the patients' community faith ministers, who have been briefed about the medical situation, can be helpful in understanding religious perspectives that differ from the clinician's, fortifying and bolstering patients' religious and spiritual support systems, and establishing the trustworthiness of the medical team.

Discrimination and Trustworthiness

Distressingly high proportions of Latinos state that they have experienced health care discrimination. In a recent, diverse, population-based survey of 42,044 adults residing in California, 13% of all Latinos and 16% of immigrant Latinos reported experiencing racial or ethnic discrimination in the health care setting.⁸⁶ Latino immigrants have qualitatively described negative patient-provider interactions, including feeling that doctors did not take enough time to educate or examine them, and did not care about them personally.⁸⁷ Perceived discrimination can have detrimental consequences for health-related behavior; for example, patients who perceive medical discrimination are less likely to undergo recommended screening for early detection of cancer.⁸⁸

Physicians and health care institutions have not always demonstrated trustworthiness. Studies have consistently found that Latinos receive lower quality care than do white patients.⁸⁹ One study of patients presenting with pain in US emergency departments found that only 24% of Latinos received an opioid compared with 31% of whites ($p < .001$).⁹⁰ Crawley advocates reframing discussions about “distrust” (which focuses the burden of change on the patients' attitudes of distrust) into a discussion of establishing the “trustworthiness” of physicians and health care systems in end-of-life care situations.^{85, 91} Clinicians in this case might have gently explored Mr M's experiences of discrimination and concerns about discriminatory withholding of medical resources, and used language that promoted trustworthiness (Table 3). It may have been helpful for clinicians to state outright that they do not tolerate discrimination in their practices and that they strive to treat all patients equally.¹

Conclusion

As demonstrated by the case of Ms C and Mr M, Latino culture exerts a profound influence on the end-of-life experience of patients and their loved ones. Cultural factors can be adequately addressed when clinicians understand Latino cultural themes prevalent at the end of life, and use universal strategies of clear health communication. In this case, clinicians might have improved care by using professional translators for important conversations; learning more about her experience prior to hospitalization (immigration experience and relationship with her partner); contacting the patient's family in Guatemala early in the course of decision making; and investigating options for transporting her to Guatemala before she became too ill for the journey. By taking time and displaying an open, interested, and respectful attitude, clinicians can learn and grow professionally while providing high quality, culturally congruent care for dying Latino patients and their families.

Box 1: Universal Strategies for Clear Health Communication

An “Ask-Tell-Ask” model has been advocated for difficult conversations at the end of life, and a related model has been advocated for patients with limited health literacy.⁹³

1. Assess prior knowledge

Ask what patients or caregivers already know or believe about a clinical situation. This allows clinicians to tailor their message and clarify misconceptions.^{93, 94}

“What have you already been told about your illness?”

2. Use simple language

Slow down one's speech, use plain, “living room,” language, avoid jargon; prioritize and limit the number of key points discussed to no more than 2 at a time during an encounter.

Say “the cancer has spread” instead of using the term “metastatic.”

3. Encourage questioning

Assume that patients have questions, rather than asking whether they do. This empowers patients to get their questions answered.⁹⁴

Do not ask “Do you have any questions?” Rather, ask “What questions do you have?”

4. Use the “teach back” method

After each key point has been discussed, confirm understanding using the “teach back” method, which is particularly effective for patients with limited health literacy.^{49, 56, 57} The “teach back” method simply asks patients or family members to restate what was just discussed. De-stigmatize the “teach back” by placing the onus of achieving good patient understanding on the clinician.

“I've just said a lot of things. To make sure I did a good job and explained things clearly, can you describe to me what we just talked about in your own words?”⁵⁷

Box 2: Questions to Improve Cultural Understanding of Illness^{95, 96}

Acculturation is the modification of a group's behaviors, values, and beliefs as a result of contact with a dominant culture. Assessment of acculturation status can help clinicians understand how Latino patients have adapted their perspectives in response to the dominant local culture (Anglo European-American in much of the United States).

In general, be open, curious, and respectful.

Preface with:

“The kinds of care we provide and the way we talk to patients may be different here than in the country you came from. I want to provide you the best possible care, so it would help me if I understood more about your culture.”

Questions to ask about acculturation:

“What language do you speak at home?”

“In what language do you watch television and/or read the newspaper?”

“Were you born in the United States?” If no, ask,

“At what age did you immigrate?” and

“How long have you lived in the United States?”

Questions to ask about patient's culture of origin (can replace “your culture” with the name of the country the patient came from):

“Tell me what I need to know about your culture (Guatemala).”

“Tell me what I don't know about your culture (Guatemala).”

“What do you think is the cause of this illness?”

“How would this illness be treated in your culture (Guatemala)?”

“How do doctors in your culture (Guatemala) talk with people about illness?”

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Resources for End-of-Life Care in the Latino Community

WEB SITES

The National Resource Center on Diversity in End of Life Care

http://www.alzorg/Resources/Diversity/downloads/HL_OUTreach.pdf (last accessed 10/27/08)

Information for clinicians on Latino attitudes and beliefs relevant to care at the end of life.

Cultural Clues. End-of-Life Care: The Latino Culture

http://depts.washington.edu/pfes/pdf/End%20of%20Life%20Care-Latino4_07.pdf (last accessed 10/27/08)

A publication of The University of Washington, Seattle. For clinicians. Contains information on the importance of family, suggested communication strategies, and rituals.

Guidelines for Use of Medical Interpreters.

<http://www.aamc.org/students/medstudents/interpreterguide.htm> (last accessed 10/27/08)

A publication of The American Association of Medical Colleges.

The Office of Minority Health

www.omhrc.gov (last accessed 10/27/08)

Information on Cultural Competence in Health Care.

BOOK

Talamantes MA, Gomez C, Braun KL. Advance Directives and End-of-Life Care: The Hispanic Perspective. In: Braun KL, Pietsch JH, Blanchette PL, eds. *Cultural Issues in End-of-Life Decision Making*. Thousand Oaks, CA: Sage Publications; 2000:83-100. This book reviews ethical, legal, and cultural issues related to advance care planning and end of life decision making, including a chapter on end of life issues and advance care planning in the Latino community.

TELEPHONE AND ONLINE INTERPRETER SERVICES

Certified Languages International(CLI)

CLI is a full-service professional language company specializing in phone interpreter and document translation services in 150 languages.

<http://www.certifiedlanguages.com/> (800/225-5254) (last accessed 10/27/08)

Language Line Services

Certified medical interpreters available 24 hours/day.

www.language.com (800/752-6096) (last accessed 10/27/08)

Tele-Interpreters

Over-the-phone interpretation, as well as translation services. (last accessed 10/27/08)

www.teleinterpreters.com (800/811-7881)

LEGAL AND SOCIAL SUPPORT SERVICES

American Immigration Lawyers Association

Free search engine that provides contact information for local immigration lawyers.

<http://www.aila.org/>

League of United Latin American Citizens (LULAC)

Web resource with contact information for local Latino councils and links.

<http://www.lulac.org/index.html>

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Table 1
Recommendations for Working with Interpreters when Communicating about End-of-life Care

Recommendation	Rationale ^{36, 92}	Words to Say
Briefing and Debriefing Interpreters should be briefed beforehand and debriefed afterward.	Briefing and debriefing each serve several important purposes: <ol style="list-style-type: none"> 1 Allows clinicians to warn the interpreter that sensitive topics will be addressed. 2 Provides an opportunity for clinicians to learn about culturally important considerations from the interpreter. 3 Provides an opportunity for clinicians to provide emotional support for the interpreters, who are otherwise left to process highly emotional meetings alone. 	Briefing: "Before we go in the room, I want to clarify that my goal in this meeting is..." "I will speak in short phrases. I need you to tell me everything the patient and family say." "Are there particular cultural concerns that you are aware of that might impact on our discussion of...?" Debriefing: "How did that meeting go for you?" "Do you have any concerns about the family's understanding?" "Do you have any concerns with what I spoke about with the patient and their family, or how I did so?"
Physical Meeting Arrangement Patients, clinicians, and the interpreter should be seated in a triangle.	Respects the patient-clinician interaction as the central focus.	"I would like us to sit in a triangle. I will talk directly to the patient and ask that you interpret everything I say."
Communication Style Clinicians should make eye contact with patients and speak directly to them in the first person.	Greater opportunity for patients and clinicians to perceive non-verbal communication.	"Please don't be offended when I address the patient directly."
Translation Clinicians should ask interpreters for direct and complete translation.	Minimizes misunderstanding and interpretation error.	"Please interpret directly and completely. If the patient says something you don't know how to interpret, please let me know that and if I say something you aren't sure how to interpret, please let me know so I can explain it more clearly."
Identify Misunderstandings Ask the medical interpreter to clarify in his or her own words when a misunderstanding might occur due to a cultural difference.	Interpreters may pick up on misunderstandings based on cultural differences that may be sources of confusion, or be missed entirely.	"If I or the patient says something that is not clear or if you think there is a potential misunderstanding happening, please let me know. I depend on you not only to interpret the words but also to be aware of the context for the conversation."
Introduce the Interpreter to the Patient Clinicians should introduce interpreters to patients in a manner that explains their presence, explains how the interpreter will be used, and addresses confidentiality concerns.	Setting expectations and clarifying confidentiality issues may reassure patients and facilitate communication. Undocumented immigrants may fear reporting of immigration status, should the topic arise, to government authorities. ¹⁶	"I want to introduce you to the medical interpreter. We are using an interpreter because the topics we are discussing are important and we need to communicate clearly with one another. I will be speaking directly with you and the interpreter will interpret everything I say." If the clinician decides to discuss immigration status: "I want to reassure you that neither I nor the interpreter will report on your status to government immigration authorities."

Table 2
Issues that May Affect End-of-Life Care for Latinos

Issues	Relevance to End-of-Life Care	Actions to Take/Words to Say
1. Communication Barriers		
a. Language barrier	Patient and medical team cannot communicate	Use of professional interpreters in person, where possible, and otherwise by telephone should be mandatory. Avoid use of <i>ad hoc</i> interpreters (adult family members, bilingual staff) except as a last option.
b. Limited health literacy or educational attainment	Patient may not have access to or understand information	Clear health communication using basic terminology and avoiding all jargon (see Box 1). Consider using simple written materials.
c. Family members or other loved ones are still in the country of origin	Patients may be more vulnerable without important caregivers	Support/encourage telephone communication or videoconferencing via Internet. "Our hospital will provide free long distance telephone calls to your family." (if available)
2. Cultural Scripts, <i>Spanish</i> (English) ^{10,26}		
a. <i>Familismo</i> (Familialism)	Family is highly valued; the cultural norm is for a collective orientation as opposed to a focus on the individual. The extended family may wish to be present at the bedside and to be involved in decision-making.	Assume that family members will be involved, although one should always check with the patient. "Are there family members who should be present and involved in your care?"
b. <i>Simpatia</i>	This refers to a cultural script that highly values positive social interactions. In the health care setting, Latino patients may desire to promote smooth and pleasant social relationships and thus may try to avoid contradicting authority figures (eg, may indicate that they understand when they do not). Patients look for positive social interactions with their physicians.	Go beyond "yes" - ask patients to repeat back information or give more detail about their understanding of concepts (see Box 1 for words to say). Pursue opportunities for "small talk" to establish some common ground.
c. <i>Personalismo</i> (Formal friendliness)	Latinos may want to feel comfortable with physicians as "friends."	Avoid being professionally distant, become comfortable discussing non-medical issues or using humor (when appropriate) or disclosing some aspects of personal life.
d. <i>Respeto</i> (Respect)	Patients need to feel respected, particularly important for Latino elders.	Always address patients formally by their last name and preceded by " <i>señor</i> " (sir) or " <i>señora</i> " (madam). Use of first names in this setting is inappropriate and may be perceived as lack of respect.
e. <i>Machismo</i> (Male chauvinism)	While this term has negative connotations of domination by men and even overt repression of women, in practice, <i>machismo</i> tends to take the form of a more benign gender role in which men feel the need to serve as protectors and providers for the family.	Make sure to respectfully explore female Latino patient's concerns and preferences in private. Latino male patients may be more likely to respond to physician recommendations if framed as being helpful or important for the family. "It will help your family prepare for the future if we discuss these issues now."
f. <i>Fatalismo</i> (Fatalism)	<i>Fatalismo</i> , or fatalism is the belief in fate, that events are controlled by others, a cultural script that may be heavily correlated with religious beliefs.	Explore the patient's sense of control and belief in their ability to alter the course of events. "When you think about your illness, how much do you think you can control what happens?" Explore how prior experiences of discrimination or lack of access to services impact influence their pessimistic attitudes about the future. "Have you had any experiences with doctors or nurses where you felt they did not treat you with respect? I ask because I want to act in a way that shows my respect for you as a person and my desire to help you."

Table 3
Examples of Strategies for Establishing and Promoting the Trustworthiness of Health Professionals^{22, 91}

Method of Communication	Words to Say
Naming the emotion	"When we talk, I feel that something is bothering you. Can you tell me more about that?"
Understanding relationships	"Tell me about how things have gone with your other doctors and nurses."
Ask about experiences of discrimination	"Have there been times when you felt you or your partner were treated poorly because you are Latino, immigrants, or do not speak English well?"
Promoting trustworthiness	"I will try to act in a way that will promote your trust in me."
Cede control back to the patient	"I would like to know if there is anything I can do to make you feel more comfortable when we talk? For example, using an interpreter every time?"
Explore outcomes of contradictory information	"I understand that some of your other doctors may have painted a more optimistic picture of your partner's illness than I have; what is that like for you?"