Among the Most Vulnerable: Palliative and End-of-Life Care for Latino Immigrants

By Tina Castañares, M.D.

Editor's Note: This article was adapted from presentations made at the Coalition's National Congress, “Recovering Our Traditions III,” held in February 2008.

Dr. Castañares has served as the medical director of the Hospice of The George in Hood River, OR, since 2003, and has maintained a continuous practice as a family physician at La Clinica del Carino in Hood River for over 20 years. She can be reached at tcastanares@hospicesofthegorge.org.

A hospice and palliative care organization everywhere is striving to reach vulnerable populations underevaluated in the past. Certainly, Latino immigrants fit this description. No data exist on utilization of hospice and palliative care services by immigrants in general, but studies suggest that only 4 percent of hospice patients nationwide are Latinos – despite their exceeding 14 percent of the U.S. population, and representing our fastest-growing ethnic or racial minority. By the year 2050, it is estimated that more than 24 percent of our population will be Latinos. Ample evidence exists that Latinos experience significant disparities in health status and access to health care. These problems are amplified for Latinos who are also immigrants.

What do we need to learn in order to improve our service to these groups? First, we must agree on certain premises. It's crucial to remember that the broad term “Latinos” encompasses a heterogeneous, complex set of cultures, each of them made up of differing individuals. Thus, generalizations about Latinos must be made judiciously and taken with a grain of salt, as is the case about any other racial, ethnic or cultural group.

In addition, cultures and subpopulations are always in evolution. Educational level, English proficiency, spiritual life, beliefs systems, literacy level and many other elements all vary within the group, and will also change within one individual over time. What a 50-year-old Catholic, Mexican-American immigrant to rural California believes about approaching the end of life is likely to be different in 20 years from what it is now. And her mindset will undoubtedly be very distinct from that of a 15-year-old Dominican-American boy born and raised in New York City.

All of this means that “cultural competency” is a road that never ends, a path rather than a destination. The journey is an honorable and essential one for those of us offering end-of-life and palliative care, but ultimately it is also a humbling one. We will always learn more from our patients than we could begin to “teach” them…or teach others about them.

That said, I have long been more interested in sharing information about certain socioeconomic realities than traditional “cultural” factors when discussing health disparities and access issues. To the extent that we can become knowledgeable about our society's demographic changes and what barriers are faced by Latino immigrants, we will be better equipped to reach them and provide services they need.

Most Latino immigrants in the United States are here legally – as lawful permanent residents or as “non-immigrants” with temporary visas. In individual communities, the mix varies. New growth communities such as Oregon, where large numbers of new Latino immigrants have arrived relatively recently, differ in many respects from areas in border states with long-established, often native-born Latino populations. In all cases, however, Latino ethnicity is an independent predictor of uninsurance, as is migration status, “documented” or not.

Where I live in the Pacific Northwest, almost all Latino immigrants work full time (or more), and they are employed principally in the agricultural, food system, nursery, construction, landscaping, hospitality and restaurant industries. They are typically from rural interior and southern Mexico, with limited education and English. Among them, uninsurance is as high as 80-plus percent. Their elders are sometimes ineligible for Medicare. Hospice and palliative care is not covered by Emergen-cy Medicaid for “non-qualified immigrants.” The latter term, introduced in 1996, includes not only undocumented immigrants but also those who are in the United States lawfully for fewer than five years. It also includes those on student, tourist and worker visas. (Non-qualified immigrants are also ineligible for standard federal Medicaid benefits, even when they meet all other criteria.)

Nationwide, immigrants are as likely as others to enroll in health insurance when it is offered in the workplace. But because their employers are less likely than others to offer such benefits, fewer than 25 percent of immigrant workers have job-based health insurance. To summarize findings of numerous studies, almost 1 in 2 non-citizens lacks health insurance. Naturalization helps, but still doesn't even the scale. Even when naturalized citizens are included, 1 out of 3 foreign-born people are uninsured.

Latino immigrants fare worse than other immigrants and worse than U.S.-born Latinos. Foreign-born Latinos are twice as likely as native-born Latinos to be uninsured (49 percent vs. 24 percent). Even the length of time living and working in our country doesn't level the playing field for Latino immigrants in the United States. Seven years, 72 percent are uninsured, vs. 28 percent of non-Latino immigrants; and among those here for over 15 years, 35 percent of Latino immigrants remain uninsured, more than double the figure for non-Latino immigrants.

These discouraging statistics are dry on the page. Let us instead imagine the potential impact on actual patients and families to whom we might offer hospice and palliative care. Before we imagine, allow me to interject a personal motto: “We don’t fix immigration policy at the patient’s bedside.” Whatever opinions one might have regarding immigration, we are called to minister to patients’ physical and spiritual needs, wherever they may be.
have a large right breast mass; enlarged, firm right axillary nodes; and exquisite tenderness over her left humerus.

It is not hard to guess that Doña Elena has advanced breast cancer, metastatic to bone, with a pathologic fracture. Is she eligible for Medicare or Medicaid? No, because she hasn’t been here for five or more years (“non-qualified immigrant,” though legally present). She may qualify for Emergency Medicaid if she meets income criteria, but it will cover only some of her ER bills – and not cancer treatment, any outpatient follow-up, medications, home health care, long-term care or hospice.

Doña Elena is now eligible for hospice care. In remembering our caveats about overgeneralization, it is still reasonable to predict that her family may say one or more of the following: “Please don’t tell her what she has.” “Please do everything you can to save her, no matter the cost.” “We will take care of her ourselves.” Her local hospice needs to be as prepared as possible in the realms of cultural proficiency, community resources and financial resources if it is to serve her and her family appropriately.

Estéban Lopez

Let’s turn our attention to Doña Elena’s son, Estéban, and his own health problems. Estéban, 53, is a disabled former farmworker, a naturalized citizen who has spent most of the past 35 years in rural Washington. Seven years ago he was badly injured on the job; his state’s plan shrank, no longer covering adults without dependent children. Estéban has a primary care provider at the local community health center, and the community hospital provides some charity care coverage that has helped him in the past.

This gentleman, who could clearly benefit from interdisciplinary palliative care, is extremely worried about his mother, his own health, and his wife. He is depressed. Some of the thoughts he is likely to have are these: “I want every treatment that has any chance of making me better.” “I don’t want to leave my family in debt.” “This is a punishment I must accept.” “This is unfair, after how hard I’ve worked.” For cultural reasons, Estéban might not complain of pain. Any one of these concerns will require artilful attention by a palliative care team. In addition, Estéban may truly need interpretation and translation, but deny that he needs it – a denial that is often too readily accepted by health care professionals.

Estéban has been diagnosed with multiple sclerosis. Symptoms were mild at first, but recently his exacerbations and complications have made him mostly bedridden. Symptoms were mild at first, but recently his exacerbations and complications have made him mostly bedridden.

This is unfair, after how hard I’ve worked.” For cultural reasons, Estéban might not complain of pain. Any one of these concerns will require artilful attention by a palliative care team. In addition, Estéban may truly need interpretation and translation, but deny that he needs it – a denial that is often too readily accepted by health care professionals.

Two years ago Estéban was diagnosed with multiple sclerosis. Symptoms were mild at first, but recently his exacerbations and complications have made him mostly wheelchair-bound. He also has worsening polyneuropathy. In the past seven months he’s gone to the local ER three times, principally for shortness of breath and once because of a fall. Estéban is uninsured. He applied four months ago for Social Security disability, which might eventually provide him with Medicare coverage – but the wait for a determination may be as long as 24 months. He’s not on Medicaid because his state’s plan shrank, no longer covering adults without dependent children. Estéban has a primary care provider at the local community health center, and the community hospital provides some charity care coverage that has helped him in the past.

This gentleman, who could clearly benefit from interdisciplinary palliative care, is extremely worried about his mother, his own health, and his wife. He is depressed. Some of the thoughts he is likely to have are these: “I want every treatment that has any chance of making me better.” “I don’t want to leave my family in debt.” “This is a punishment I must accept.” “This is unfair, after how hard I’ve worked.” For cultural reasons, Estéban might not complain of pain. Any one of these concerns will require artilful attention by a palliative care team. In addition, Estéban may truly need interpretation and translation, but deny that he needs it – a denial that is often too readily accepted by health care professionals.

Guadalupe Lopez

Finally, let us consider the case of Guadalupe, Estéban’s wife. Fifty years old, in the United States for the past 20 years but undocumented, she is uninsured and uninsured. She had always worked at least two part-time jobs, most recently in a fruit packing plant and as a child care provider, but six years ago she suddenly developed serious health problems. Guadalupe was diagnosed with autoimmune hepatitis, a quintessential “bad luck” illness; there is nothing she could have done to prevent it, and she had no risk factors. Within a few months on her multiple lifesaving medications (including corticosteroids), she developed insulin-dependent diabetes, peptic ulcer disease and chronic anemia. More recently, her medication-induced osteoporosis and other skeletal problems have resulted in several spinal compression fractures, pelvic fractures after a mild fall, loss of her teeth, and the need for bilateral hip replacements. Pain-related inactivity has led to obesity and has contributed to depression.

Guadalupe, ineligible for Medicare or Medicaid, has the same family physician as her husband, and has benefited from the hospital’s patient assistance program. The health care providers who know her best note the following: her greatest fears relate to losing her care giving ability for her grandchildren, husband and mother-in-law. She often denies pain verbally, but moans as a sign of pain. She has ambivalent feelings toward medications (they have hurt her, and they have saved her life) and about the local hospital (they have helped her, but they always talk about dying and advance directives). Guada-

Finally, let us consider the case of Guadalupe, Estéban’s wife. Fifty years old, in the United States for the past 20 years but undocumented, she is uninsured and uninsured. She had always worked at least two part-time jobs, most recently in a fruit packing plant and as a child care provider, but six years ago she suddenly developed serious health problems. Guadalupe was diagnosed with autoimmune hepatitis, a quintessential “bad luck” illness; there is nothing she could have done to prevent it, and she had no risk factors. Within a few months on her multiple lifesaving medications (including corticosteroids), she developed insulin-dependent diabetes, peptic ulcer disease and chronic anemia. More recently, her medication-induced osteoporosis and other skeletal problems have resulted in several spinal compression fractures, pelvic fractures after a mild fall, loss of her teeth, and the need for bilateral hip replacements. Pain-related inactivity has led to obesity and has contributed to depression.

Finally, let us consider the case of Guadalupe, Estéban’s wife. Fifty years old, in the United States for the past 20 years but undocumented, she is uninsured and uninsured. She had always worked at least two part-time jobs, most recently in a fruit packing plant and as a child care provider, but six years ago she suddenly developed serious health problems. Guadalupe was diagnosed with autoimmune hepatitis, a quintessential “bad luck” illness; there is nothing she could have done to prevent it, and she had no risk factors. Within a few months on her multiple lifesaving medications (including corticosteroids), she developed insulin-dependent diabetes, peptic ulcer disease and chronic anemia. More recently, her medication-induced osteoporosis and other skeletal problems have resulted in several spinal compression fractures, pelvic fractures after a mild fall, loss of her teeth, and the need for bilateral hip replacements. Pain-related inactivity has led to obesity and has contributed to depression.

Finally, let us consider the case of Guadalupe, Estéban’s wife. Fifty years old, in the United States for the past 20 years but undocumented, she is uninsured and uninsured. She had always worked at least two part-time jobs, most recently in a fruit packing plant and as a child care provider, but six years ago she suddenly developed serious health problems. Guadalupe was diagnosed with autoimmune hepatitis, a quintessential “bad luck” illness; there is nothing she could have done to prevent it, and she had no risk factors. Within a few months on her multiple lifesaving medications (including corticosteroids), she developed insulin-dependent diabetes, peptic ulcer disease and chronic anemia. More recently, her medication-induced osteoporosis and other skeletal problems have resulted in several spinal compression fractures, pelvic fractures after a mild fall, loss of her teeth, and the need for bilateral hip replacements. Pain-related inactivity has led to obesity and has contributed to depression.

Finally, let us consider the case of Guadalupe, Estéban’s wife. Fifty years old, in the United States for the past 20 years but undocumented, she is uninsured and uninsured. She had always worked at least two part-time jobs, most recently in a fruit packing plant and as a child care provider, but six years ago she suddenly developed serious health problems. Guadalupe was diagnosed with autoimmune hepatitis, a quintessential “bad luck” illness; there is nothing she could have done to prevent it, and she had no risk factors. Within a few months on her multiple lifesaving medications (including corticosteroids), she developed insulin-dependent diabetes, peptic ulcer disease and chronic anemia. More recently, her medication-induced osteoporosis and other skeletal problems have resulted in several spinal compression fractures, pelvic fractures after a mild fall, loss of her teeth, and the need for bilateral hip replacements. Pain-related inactivity has led to obesity and has contributed to depression.

Finally, let us consider the case of Guadalupe, Estéban’s wife. Fifty years old, in the United States for the past 20 years but undocumented, she is uninsured and uninsured. She had always worked at least two part-time jobs, most recently in a fruit packing plant and as a child care provider, but six years ago she suddenly developed serious health problems. Guadalupe was diagnosed with autoimmune hepatitis, a quintessential “bad luck” illness; there is nothing she could have done to prevent it, and she had no risk factors. Within a few months on her multiple lifesaving medications (including corticosteroids), she developed insulin-dependent diabetes, peptic ulcer disease and chronic anemia. More recently, her medication-induced osteoporosis and other skeletal problems have resulted in several spinal compression fractures, pelvic fractures after a mild fall, loss of her teeth, and the need for bilateral hip replacements. Pain-related inactivity has led to obesity and has contributed to depression.

Finally, let us consider the case of Guadalupe, Estéban’s wife. Fifty years old, in the United States for the past 20 years but undocumented, she is uninsured and uninsured. She had always worked at least two part-time jobs, most recently in a fruit packing plant and as a child care provider, but six years ago she suddenly developed serious health problems. Guadalupe was diagnosed with autoimmune hepatitis, a quintessential “bad luck” illness; there is nothing she could have done to prevent it, and she had no risk factors. Within a few months on her multiple lifesaving medications (including corticosteroids), she developed insulin-dependent diabetes, peptic ulcer disease and chronic anemia. More recently, her medication-induced osteoporosis and other skeletal problems have resulted in several spinal compression fractures, pelvic fractures after a mild fall, loss of her teeth, and the need for bilateral hip replacements. Pain-related inactivity has led to obesity and has contributed to depression.

Finally, let us consider the case of Guadalupe, Estéban’s wife. Fifty years old, in the United States for the past 20 years but undocumented, she is uninsured and uninsured. She had always worked at least two part-time jobs, most recently in a fruit packing plant and as a child care provider, but six years ago she suddenly developed serious health problems. Guadalupe was diagnosed with autoimmune hepatitis, a quintessential “bad luck” illness; there is nothing she could have done to prevent it, and she had no risk factors. Within a few months on her multiple lifesaving medications (including corticosteroids), she developed insulin-dependent diabetes, peptic ulcer disease and chronic anemia. More recently, her medication-induced osteoporosis and other skeletal problems have resulted in several spinal compression fractures, pelvic fractures after a mild fall, loss of her teeth, and the need for bilateral hip replacements. Pain-related inactivity has led to obesity and has contributed to depression.

Finally, let us consider the case of Guadalupe, Estéban’s wife. Fifty years old, in the United States for the past 20 years but undocumented, she is uninsured and uninsured. She had always worked at least two part-time jobs, most recently in a fruit packing plant and as a child care provider, but six years ago she suddenly developed serious health problems. Guadalupe was diagnosed with autoimmune hepatitis, a quintessential “bad luck” illness; there is nothing she could have done to prevent it, and she had no risk factors. Within a few months on her multiple lifesaving medications (including corticosteroids), she developed insulin-dependent diabetes, peptic ulcer disease and chronic anemia. More recently, her medication-induced osteoporosis and other skeletal problems have resulted in several spinal compression fractures, pelvic fractures after a mild fall, loss of her teeth, and the need for bilateral hip replacements. Pain-related inactivity has led to obesity and has contributed to depression.