

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

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*H*ospice and palliative care organizations everywhere are striving to reach vulnerable populations underserved 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 caveats. 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, belief 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 recent 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 immigration 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 Emergency 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 fewer than five years, 72 percent are uninsured, vs. 28 percent of non-Latino immigrants; and among those here for over 15 years, 33 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, whoever they may be.

Family Complexities

So please picture the complex, multigenerational family of Estéban and Guadalupe Lopez (not their real names), who live in a small town in Washington state. They are a middle-aged immigrant couple who have been married for 30 years; and each has serious chronic health problems. They have four adult children, ages 19 to 30, three of whom are married. These children were born in Mexico but obtained lawful permanent residency many years ago; one, like their father Estéban, has already become a naturalized citizen. Although their father speaks quite a bit of English, their mother remains monolingual in Spanish. The children are bilingual, two of them college educated. Among their spouses are two Latinos, one an unauthorized immigrant with limited English and education, and the other a native-born, college-educated U.S. citizen. The non-Latino spouse speaks only English. Estéban and Guadalupe have nine grandchildren, all of them native-born U.S. citizens, and only four of them are truly fluent in Spanish. Finally, the family brought Estéban's elderly mother, Doña Elena, from rural Mexico to live with them for the remainder of her life. She was healthy when she arrived three years ago, and her application for lawful permanent residency is in process (she is living legally in the United States).

Let's "unpack" that family – its different generations and circumstances – and analyze what challenges might emerge if palliative or hospice care were indicated.

Doña Elena

Doña Elena comes first, as elders and children virtually always do in Latino families. She is a 75-year-old, non-literate, authorized resident of the United States who is monolingual in Spanish and in her fourth year since legal entry. Doña Elena has never been hospitalized before, and when she was last seen by a health care professional more than five years ago, she appeared well. Now she is taken to the local emergency room by her son with sudden, severe upper arm pain that has not improved over a two-day period. The ER doctor finds her to

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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 partnerships 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 workers' compensation case closed 19 months later. 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 emphysema. 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 outpatient 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 artful 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 unable to provide service in Spanish.

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 uninsurable. 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 Medicaid or Medicare, 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). Guadalupe does not always appear confident or permitted to speak for herself. She is thought to be using traditional Mexican remedies, and even to be receiving prescription medicines from relatives in Mexico. In fact, Guadalupe has recently become preoccupied with thoughts about her homeland and her faraway family of origin.

Guadalupe is not hospice-eligible, but like Estéban, she could certainly benefit from interdisciplinary, outpatient palliative care if it can be found in her community. In particular, skilled medical chaplaincy care might help with her spiritual and existential needs. Once again, it is not hard to imagine the cultural-proficiency, financial and linguistic resources that will be needed to provide Guadalupe with compassionate and appropriate care. No one organization or agency can do this alone. "It takes a village" – that is, strong community partnerships – in cases like hers.

We are all familiar with the concept of holding family conferences when supporting patients and caregivers. However, the multigenerational complexity of the family described above is a reminder that convening "a family conference" can be a naive oversimplification. Speaking with Estéban in English, for example, will exclude his mother and his wife, but speaking with those elders in Spanish will exclude some of the younger two generations, likely be very involved in direct caregiving. Attitudes, beliefs, assimilation within the larger U.S. culture, and familiarity with our health care system

vary significantly within this extended family. Knowing and accommodating these variables is part of our challenge in providing needed services.

Family Assets

Guadalupe, Doña Elena and Estéban head up a family with many medical, psychosocial and spiritual needs and challenges, and they face significant barriers to accessing needed care. But our discussion would be woefully incomplete without identifying the many assets this family has brought already to the table, and will be able to tap in future difficulties.

As is well known in their community, they have strong spiritual faith and church involvement. They are well supported by fellow parishioners and by clergy. The family is a close group, mutually committed to one another. One of the adult children has worked as a CNA, and another as a medical office manager. All four of them are avid Internet users and, with the help of the providers and educators at their community health center, have learned to identify reliable Web sites for health care information. Six grandchildren live locally and are wildly devoted to their grandparents, visiting them after school most days; as they grow older, they recognize their new role in helping with household tasks. This family, in short, will certainly benefit from more professional services, but already has vital strengths to help them do the hard work required by chronic illness, increasing disability, dying, death and grieving.

In conclusion, both our individual organizations and the hospice and palliative care movement must prepare ourselves with knowledge, develop key partnerships, and advocate for compassionate, skilled care for all patients and their families – working to remove and overcome societal barriers wherever they exist. Among the essential partners in serving Latino immigrants are community and migrant health centers, churches, and existing coalitions for immigrant or Latino rights. One strategy for becoming more skillful in outreach, needs assessment and direct service – the utilization of community health workers – still new to the hospice and palliative care movement, but proving to be enormously useful in primary care and public health. These community health workers are sometimes called *promotores de salud*, or lay health promoters. For now, philanthropic support is essential for most of us in the field committed to such work. We should hope and strive to achieve systematic funding in the future. 