

New Lives—Latinos, Cancer, and Spirituality: An Ethnographic History

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Editor Introduction

Through an in-depth ethnographic history the medical student author sees his Latino patients as a product of a defunct health care system, which misses its goal in name and function. The stories that emerge bring deep understanding necessary for diagnosis and treatment.

As part of a Principles in Clinical Medicine assignment, I was able to interview a Latino family. Luis and Isabel are a pleasant Hispanic couple who are open and accurate historians. They speak fragmented English, but seem to have excellent comprehension. We had little difficulty communicating, though they both prefer to speak in Spanish. They insist that their three children speak Spanish around the house; in fact, Luis says he pretends not to understand English when the children speak it around the house. Luis and Isabel both speak English when out in public to try to avoid the discrimination they both experienced when they first came to the US and could not speak English.

Household Composition

There are currently five people living in their house: —*Luis* was born in Mexico City and lived there until 11 years ago when, at age 18, he “just decided” to come to the US. He is in the process of obtaining a green card. He stated that it was important because “unlike illegal immigrants, [he has] rights, and knows them so that [he doesn’t] believe or let threats, insults, and discrimination bother or scare him.” —*Isabel* was born in Mexico and came to the US nine years ago with her first husband who was stationed in Mexico with the US military. After living in the US a couple years her husband began to act violently towards her and their daughter. With the help of friends she was able to escape and was introduced to Luis by another friend. She had obtained her green card when she moved to the US with her American husband. —*Pilar* is Isabel’s daughter from her first marriage. She is 15, was born in Mexico and has lived in the US

nine years. Because of her father’s American citizenship, she is a US citizen. She is in ninth grade, speaks English fluently, and attends the local high school. —*Linda* is Luis and Isabel’s first child. She is seven and was born in the US. She is in first grade and speaks English fluently. —*Stephen* is Luis and Isabel’s youngest child. He is five, was born in the US, and recently began kindergarten.

Material Possessions, Transport, and Family Support

Luis and Isabel rent an 850-square-foot three-bedroom apartment, which was very clean when I visited. They have a TV without cable, an old VCR player, a DVD player, and a ministere. The apartment is sparsely furnished with basics, such as a dining room table and chairs, a couch, but no extra furnishings such as end tables, lamps, bookshelves, etc. They have two older cars, a 1992 Chrysler minivan, and a 1989 Pontiac Fiero. When talking about the cars, Isabel chimed in that “usually only one is working at a time, and Luis has to use it to get to work.” There was a clean birdcage in the corner of the dining room, which held three parakeets, their only pets. While talking about the birds, Luis recounted how two birds had escaped last week while the children were playing with them, so they had purchased replacements. I asked about family and Luis mentioned that he has many uncles, aunts, and cousins in the area, but is only in contact with his brother who lives nearby. Similarly, Isabel mentioned that she has no family here and actually wanted to go back to Mexico sometime in the future because she misses the support provided by her large family.

Housing Costs

The major expense for Luis and Isabel, aside from health care, is rent, which Luis pays. They moved into their apartment just one month ago because rent at their former residence had become too expensive. They are quite satisfied with their new home and happy to be settled down, although Luis mentioned that he hopes to be able to save so they can stop “just paying, paying, paying for rent,” and purchase a

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small home to begin compiling assets. He said that it will probably be more than a year before they will be in a position to even consider purchasing a small home.

Family Work History and Income

Luis is employed by a company that makes custom acrylic plastics. Isabel works at the YMCA and uses her income to buy the food and for other expenses such as clothes for the children, etc. They are also struggling to pay past health care expenses and have been awarded some assistance/charity finance programs, but they still need to make monthly payments. Luis told us that he would rather spend time with his wife and children and have a little less money than his brother who works constantly and misses his family.

Medicines and Herbs in the Home

They have the usual over-the-counter medications such as ibuprofen and acetomenophin, which are stored in a secure cabinet in Luis and Isabel's bedroom. They do not take any medications on a regular basis or use any supplements, such as herbs, etc.

Folk-Medicine Beliefs and Practices

When I asked about traditional Mexican medicine, we discovered that, for the most part, people in the cities in Mexico use Western medicine. Like here in the US, health care is dependent on the type of job and how much money you have. Good jobs in Mexico provide health insurance with no copays. In the case of emergencies, they contrasted the emergency room in Mexico with those in the US, saying that "[In Mexico] it doesn't matter how severe your injury is, but rather how much money you can pay. The rich people with lots of money will get their small cut treated while a poor person with major bleeding or a heart attack waits to be treated—so I think it is a little better in America." However, Isabel did mention that outside the urban areas, you could find traditional healers. She said many people use their traditional medications for common illnesses, such as colds, but turn to Western medicine when they have more serious problems. She mentioned that their primary traditional medications consisted of "ground-up leaves mixed with different pastes." Luis said that he uses the traditional medication of virgin honey and lemon to cure any colds or mild illnesses he might have, and believed that they help him improve. They also mentioned that they are Christians and believe in miraculous healings.

Health Problems in the Family

Luis is the only one in the family with health insurance. His job provides Kaiser Permanente insurance,

with which he is very satisfied; however, it is much too expensive for them to buy into the family plan through Luis's work, which leaves everyone else uninsured. Fortunately, the children have been healthy. If any problem ever arises they go to the doctor at a free clinic that has Spanish-speaking employees or interpreters. Through the clinic they have received their vaccinations. Unlike Luis and the children, Isabel has had several major health problems.

When I asked Isabel about her health, she began by telling us how she has fought "pelvic" cancer. She said she felt a lump when she was sitting down three years ago, and went to a free clinic to have it checked out. They referred her to Oregon Health and Science University, where she was diagnosed with cancer. She underwent ten operations to remove the cancer, at a cost of \$2000 per operation. I asked her Arthur Kleinman's eight questions for eliciting the patient's explanatory model of his/her illness¹ about her cancer, which were a little difficult for her to understand, but she answered as best as possible. She mentioned that she felt funny after using a dirty toilet in the restroom at a gas station shortly before noticing the lump, and wondered if that might have had something to do with causing the cancer. She elaborated that she was "numb to the world" for three weeks after getting the diagnosis. She was very worried about what would happen to her two-year-old son and four-year-old daughter if she wasn't around. She was concerned that they would not have a good person to look out for them, especially with so little family in the area. Jokingly she added that, "I wasn't worried about Luis—he'll find another wife and be okay, but my children—I was very worried about them." She realizes her disease will have a long course. She was happy with the care she received and said she was not interested in traditional medicine to treat her cancer. She hopes she'll have enough time to raise her children until they can take care of themselves. Following the surgeries, which were "successful," she went through a course of chemotherapy, during which she was diagnosed with diabetes.

Isabel began to lose some of her eyesight in one eye because of macular degeneration, which she attributed to the chemotherapy. She realizes that diabetes is a lifelong disease and prays that her diabetes will stay under control. She said every time it has been checked since she started praying, the glucose has been within the normal range; however, she does not check her sugar at home or on a regular basis. Surprisingly, she was not very worried about losing the vision because she could still be around to help her children even if she couldn't see them. Because of the expense, she has not had an eye exam in two years.

If we had not asked the questions we did, we would never have understood the difficulties and intricacies of their situation.

The high cost of health care has limited her access and desire to pursue more than the most essential care. They applied for and received a discount on her cancer care, yet still have credit agencies billing them. She said, “I just ignore [the credit agencies] now because I have to get food for the family—I can’t pay the bill. We try to pay the \$100/month payment plan, but it is still such a struggle, sometimes we just can’t make the payment.”

Following the story about her cancer, I asked if she’d had any other health problems, and with some hesitancy, Isabel shared a fascinating story that took place seven years ago. She was three months pregnant with Linda and began to experience severe cramping in her lower abdomen. She went to the doctor, who diagnosed her with an ectopic pregnancy and insisted that they rush to the hospital for surgery. Instead Isabel and Luis went to their church and prayed. They went home afterwards and waited. Two days later they returned to the same doctor who was very angry that they hadn’t gone for surgery. He yelled at them and sternly remarked that she had made a serious mistake and endangered not only her life, but the fetus’s as well. Isabel was bothered and told him that she was not ready to give up her baby, and that it bothered her that he called her baby a fetus, yet he continued to call it a fetus. However, when he performed the ultrasound, the baby had moved from the fallopian tube into the uterus, much to the amazement and disbelief of the doctor. They attributed this miracle to their prayers, and since then, in addition to Western medicine, they have had a devout reliance on their Christian faith for their medical needs. Luis summed it up saying, “God is the best doctor. God helps a lot.”

Health Hazards Around the House

Isabel and Luis are very good at keeping medicines and other dangerous household items such as cleaning agents, etc, out of reach of their children. I did not observe any major health hazards around the house.

Risk Factors for Inadequate Health Care

The primary risk factor for Luis and Isabel’s family is lack of access to health care and health education. Their financial limitations have prevented them from using care and receiving optimal preventive care such as diabetes education, eye appointments, and dental care. Nonetheless, I was extremely impressed with the family’s outlook and approach to life given their difficult situation. At the end of the interview, Luis and Isabel told us a story about how many of their immigrant friends will not get any health care at all because of fear of being turned in to the Immigration and Naturalization Service (INS). They recounted how one friend in particular had avoided any

prenatal care, and delivered her baby in her own living room with only her husband and daughters to help her because she was afraid of being turned in to INS. Thankfully Isabel and Luis have been able to access some care, but for them, and for many of their friends, their access to care is inadequate because of legal and financial limitations—an issue we as physicians and leaders in the medical community must address.

Reference

1. Kleinman A. *The illness narratives: suffering, healing and the human condition*. New York: Basic Books; 1988.

Analysis and Personal Reflections Health Systems

Luis and Isabel were an extremely pleasant couple to visit. They welcomed me into their home, offered me juice, and openly answered my personal and probing questions. We laughed together and enjoyed a wonderful conversation—they are good people. If I had not asked the questions I did, I would never have understood the difficulties and intricacies of their situation. I would not have known how much Isabel cherishes each day she has with her children or each moment she watches them because she never knows when her cancer will return or her eyesight will fade. I would not have known how they moved to a smaller apartment in order to try to pay their medical bills.

Is this just the way life goes? Or are situations like Luis and Isabel’s the result of a flawed system? Clearly, life is not fair, but do we exacerbate the unfairness of our world by the system we use to deliver health care?

The numbers are gut-wrenching: 43 million uninsured people—good people, like Isabel and her children. We spend almost twice per capita what other modern nations do on health care—14% of our gross domestic product (GDP)! Still, people are left without any insurance at all, forced to cover the rising costs of health care on their own. When bad things happen, like Isabel’s cancer, they are left with nothing.

Individual situations, like Isabel’s, highlight the growing need for change in our system. Yet how can we change? With 14% of GDP spent on health care, a lot of people are making a tremendous amount of money through this system and will exert a major effort to prevent losing that income. Thus, a strong force will be needed to make the necessary changes. We need a system that will provide preventive care for everyone, a system that strives to keep all people healthy and heals them when they become ill. A new model is needed and development of that model is going to require a close partnership between physicians and government. Yet delivering the necessary primary and preventive care to 43 million more people will require more providers than simply physicians.

In this new model of primary/preventive care, there will need to be an increased partnership between physicians and allied health members such as physician assistants and nurse practitioners. Because there are not enough practitioners to handle all the needed primary and preventive care, we must train preventive care educators, fol-

lowing the model of diabetes educators. Because it would be a one-payer system, the cost of training and providing this preventive care should easily be recovered through reductions in more expensive procedures. More importantly than just recovering costs, this would result in better health and better quality of life for everyone.

Government will need to play a significant role, as the spectrum of care available should be the same in any place in the nation and no private company or corporation could provide for everyone. Expansion/modification of Medicare/Medicaid that could be funded by a corporate tax (the money that companies are already paying for health insurance) and may be an interesting way to begin to approach this issue without having to create a whole new infrastructure. If such a system were in place, Isabel would not be in such a horrible plight financially and could also be receiving diabetes education and screening, which might have brought attention to her diabetes earlier and prevented her macular degeneration. Her children could be receiving well-child visits and health education so they could learn how to live healthier lives.

For this to take place within the existing infrastructure, a great philosophical shift from rationing patients to rationing services is required. It is fundamentally wrong for legislative budget committees to decide, "We don't have enough money to cover Isabel and her children—she's not poor enough, so they'll just have to figure something else out." Until this transition takes place in politicians as well as voters, it will be very difficult to make the necessary changes in the system.

Health Literacy

Health literacy is a major issue for Luis and Isabel, along with most people in our system who are not fluent in English. They seemed to understand basic concepts of experiences they had had such as what was cancer, how the surgeries had fixed it, why chemotherapy had been needed, and Isabel mentioned that they always get a medical interpreter if the clinician does not speak Spanish. However, it seemed they did not have a solid understanding of diabetes, a subtle, complex and chronic condition. They did not understand that the macular degeneration was caused by the diabetes and not her chemotherapy. Isabel was overweight and had significant abdominal fat, which, combined with the declining vision, indicated that she was at high risk for more complications from her diabetes. Furthermore, she did not monitor her glucose levels, so it is hard to judge whether or not the diabetes was actually under control, or whether she just happened to be at lower levels when she visited the physician. She was beginning to suffer the effects of diabetes because she did not understand how the disease worked, and how important treatment was, highlighting the lack of health literacy. A good system of preventive care, which could be provided by a national health system, could address these issues.

Occupational and Environmental Hazards

Compounding the difficulties of the situation faced by many low-income families without health insurance is that they are often forced to work in places where they are exposed to more health-compromising hazards. Luis is fortunate to have an employer who offers health insurance, but he is still exposed to hot plastics and any gases they may put off while forming the custom plastics. It would be important to be aware of this exposure if he began having any respiratory or dermatological symptoms. Although often disparaged as a nuisance, the role that Occupational Safety and Health Administration plays in protecting people from potentially dangerous environments is very important and is one example of how having a better system in place has prevented many injuries and hazardous exposures, saving lives and reducing the health care burden that would have been caused by workplace injuries and their consequences.

Spirituality in Medicine

It is crucial for physicians to remember the role that spirituality plays in our patients' lives. We are so focused on the important scientific details and evidence-based research, it is easy to overlook the impact a patient's spirituality can have on their health condition. For Luis and Isabel, it played a central role in their approach to health care and medicine. As Luis said, "God is the best doctor." As their physician, it would be important to be sensitive to their desire to incorporate prayer into their care. Actions such as calling on hospital clergy when Isabel was preparing for her surgery might help to foster a good relationship with them. Furthermore, when patients do things that seem unfathomable to us, such as not going for treatment when an ectopic pregnancy has ruptured, or is about to rupture, we need to be sensitive to their decisions and try to educate the patient in a calm and open manner. We also need to be open to the reality that "miracles" can and do occur in medicine.

My time with Luis and Isabel served to crystallize my understanding of several topics covered in the Principles of Clinical Medicine course. However, its greatest impact came in bringing the reality of the situation in medicine and the health care system in the US to the forefront of my thinking. Having established an understanding of the system throughout this class allowed me to see Luis and Isabel's situation more clearly. Rather than simply viewing it as a difficult situation, I now see clearly how it is the product of a defunct health care system, which misses its goal in name as well as function. We need a *health* system accessible to everyone whose primary mission is to promote good health in addition to caring for the sick. ❖

Disclosure Statement

The author(s) have no conflicts of interest to disclose.