

CULT COMMUNU



URRAL NICATIONS

A multicultural look at health & wellness

BY STEPHANIE STEPHENS

CULTURAL backgrounds influence how people access and use the healthcare system, which is particularly relevant to lupus because the disease especially targets women of color. In the United States, lupus is two to three times more prevalent among Asians, African Americans, Hispanics, and Native Americans, including people in Hawaii and Alaska.

As a Chinese American woman living with lupus, Karen Ng realizes the important role that culture can play in understanding and living well with illness. For her, educating members of the Asian community about lupus is not only personally relevant, but it is also her profession. Ng is Senior Program Coordinator for Lupus Asian Network (LANtern), a nationwide, telephone-based bilingual support program at the Hospital for Special Surgery in New York City. LANtern was established to recognize cultural needs of the Asian community, with a peer health education model of counselors and bilingual lupus educational materials.

"In Chinese, 'lantern' is the beacon that lights the way," Ng explains. "Patients thank us for helping them 'see the light' and looking on the 'bright side' of managing their lupus."

Ng says that long-held cultural ideas may limit a physician's ability to successfully treat Asians with lupus. For example, patients who are ill may not question the physician's authority out of respect, yet may go home and self-medicate with herbs without informing their doctor. Although research has not been done on all herbal supplements, taking certain herbs with prescribed medications can be dangerous. This is compounded by the fact that patients may also self-adjust their medications because they perceive Western treatments as more harmful and dislike their side effects.

Misconceptions about a disease like lupus also can color attitudes about the illness itself. Ng recalls that when she was first diagnosed with lupus, her mother felt extreme guilt and blamed herself for causing the illness; many Chinese believe disease is "passed down" or caused by specific actions.

Ng also notes that depression frequently accompanies lupus and requires early diagnosis and intervention, yet it is not an accepted problem to talk about in Asian culture. The reluctance to complain until symptoms become more serious may prevent people with lupus from seeking medical care. Many people are unaware of the physical and emotional burdens of the illness on individuals and their families.

LANtern health educators emphasize the value of communicating with doctors and working closely with them to customize coping strategies for both the body and the mind.

Thuy Ly was born in Vietnam and came to the United States in 1998 when she was 17 years old. About seven months after her arrival in Colorado, she was diagnosed with lupus by the doctors at Exempla Saint Joseph Hospital in Denver.

"The term 'lupus' is something very

strange and new to my Vietnamese culture and also to my family," says Ly, who now lives in Anaheim, Calif. "At first, I asked a family friend who speaks English to go with me to the doctor appointment so she could help me to translate. Then I went to school and learned English."

Ly goes on to say that even some Vietnamese doctors do not know about lupus; when she first consulted her former physician, who also was Vietnamese, about her lupus, he asked her, "What is that?"

After finding out that lupus had affected her kidneys, Ly realized she needed a higher level of care and now sees an internist/nephrologist with whom she's comfortable. She has become increasingly knowledgeable and conversant about her disease, which includes peritoneal dialysis—accomplished through a stomach catheter.

Ly explains that in Vietnamese culture, people don't talk about everything like Americans do: "A Vietnamese family does not seek help and counseling for family matters like most Americans do," she says. "My family has very little understanding about lupus. The only thing they know is that something has made me sick all the time. They are always there for me, but sometimes it gets very frustrating to manage my health when I have to explain everything to my family and other health professionals."

She adds, "Asians may not talk about sensitive issues [but] lupus challenges you to take care of yourself, to hang in there," she says. "I'm learning and am lucky I can connect to others—my doctor, the nurses. I feel fortunate. I've become a stronger person."

Knowledge is power, agrees Valencia McCree, M.A., a nurse in Baltimore, Md., who urges people with lupus to become their own advocates. McCree, 35, is an African American who was diagnosed with lupus when she was 17. At the time, she was living in Alabama and had just recovered from a bout with chicken pox, but the lupus diagnosis took more than a year.

"I had fatigue, joint aches and pains, but no butterfly rash," she remembers. "You couldn't see my symptoms on an X-ray." One physician even prescribed Valium for her, and McCree remains perplexed to this day about that.

Today, even as an "on-the-inside" healthcare professional, McCree has to stand up for herself. "I do feel that, when I see a healthcare provider, they make the assumption that because I'm a nurse, information can be left out."

Now participating in a "wonderful client relationship" with her physician, McCree reminds us that every individual and his or her disease is different. "Lupus isn't black and white. It's all these shades of gray."

THE COMMUNICATION BALANCE

Maria E. Suarez-Almazor, M.D., Ph.D., deputy chair of research and head of the Section of Rheumatology at the University of Texas M.D. Anderson Cancer Center in Houston, believes doctors share responsibility for the balance of communication between themselves



and their patients. The ideal situation is a "balanced dialogue" between the individual with lupus and the physician, she says.

But barriers to communication can have many causes.

For example, Suarez-Almazor knows that, since most people with lupus are women, and physicians are often male, women with lupus may feel intimidated. "Sex and birth control are very important subjects, but females with lupus may be embarrassed to bring this up."

She adds that language barriers also may impede patients' understanding of their doctor's instructions, such as the correct medication dosage. "They don't want to be perceived as not being bright or as being poorly educated," she says, "so they'll remain silent. But if they hesitate to ask questions, they could be perceived as having low health literacy."

Laura Robbins, D.S.W., vice president of education and academic affairs at the Hospital for Special Surgery, and associate professor at Weill Medical College in New York City, proposes that



is a renowned lupus researcher at the University of Alabama at Birmingham, and is well known for her contributions to the LUMINA project (LUPus in MInority populations: NAture versus nurture), a database of information about Caucasians, Hispanics, and African Americans with lupus. In her work she has consistently found barriers to optimum healthcare to be linked to lack of education and lower socioeconomic status.

THE ROLE OF THE FAMILY

Family often plays a key role in a person's attitude toward their disease and their acceptance of healthcare.

"For example, a young woman may say, 'I don't believe in injections,' or 'I don't need that infusion and I'll take pills' because those close to her, like her mother or members of the church, advise her," Alarcón says.

Robbins says that the Latinas who participated in one of her research studies sought approval of their male partners, and when specific questions were addressed to the female patient, the male often answered them. "The family was consulted first, and it was important that they condoned the female's study participation," she recalls.

Ana Quintero del Rio, M.D., M.P.H., F.A.A.P., is an associate professor at the Ponce School of Medicine and the San Juan Bautista School of Medicine in Puerto Rico. She also practices at San Jorge Hospital for Children, a private clinic. "Some patients have their whole family participating in their care, while others may rely on an authority figure in the family such as the father."

But Quintero stresses that the more the physician knows about the cultures of his or her patient population, the better compliance will be in the patient-doctor relationship. "Hispanics in Puerto Rico are a mix of more than one culture: Spaniards, Africans, and our native Indians, and that may influence

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language be viewed as an expression of culture, but with caution: "The inability to speak English does not equate to culture. For the physician and caregiver to connect with the patient, those who translate need to explain that specific terminology may not always exist in that particular language, and that there are culture-specific connotations."

Graciela S. Alarcón, M.D., M.P.H.,

"When the education level is low, patients simply may not have a clear understanding of what disease is or what it can do. When a person prescribed certain medications does not follow through, not only because of cultural reasons, but also due to a poor level of understanding, patient compliance suffers, as does their overall health," Alarcón says.

how they view their disease. Doctors are more successful when they learn where their patients come from and what the culture has experienced," she says.

TIME FOR TREATMENT

A close patient-physician relationship may even help prevent lupus flares, says Jan Hillson, M.D., an internist and rheumatologist at Cambridge Health Alliance and a clinical faculty member at both Harvard University and the University of Washington. Hillson sees her lupus patients frequently during periods of flare, and she usually has them come in every one to three months to monitor disease activity and adjust medications.

Hillson believes that the admirable work ethic of some cultures, together with a stoic "this-is-how-it-is" mentality, may hinder some individuals from

seeking optimum healthcare. She recalls a Brazilian woman with lupus who continued to work as a housekeeper for three years despite rashes, painful swollen joints, and eye involvement that made it impossible to tolerate sunlight. When convinced by her family to seek treatment, her first words were, "When can I return to work to support my family?" Fortunately, her symptoms were greatly improved by medication.

Living in a remote location and lack of finances can also impact healthcare. "People who must sacrifice time and paychecks to go to a doctor are more likely to put up with symptoms," she says. Hillson once treated a young Native American male with lupus who had very serious kidney involvement and lung disease. He worked as a fisherman off the Olympic Peninsula in Washington. Although he was well-insured through



the Indian Health Service, the only rheumatologists were more than six hours from his home.

"He was the sole support of his family," Hillson remembers. "He told me, 'I don't get money for sick leave. I get money for fish.' When the fishing boat went out, so did he, and treatment for his lupus took second place."

THE THREE-LEGGED STOOL

Once in the doctor's office, "a person who is of Native American or Alaskan native descent may exhibit a history of distrust of the dominant culture that comes from pretty obvious historical factors," observes Jim Jarvis, M.D., a professor of pediatrics at the University of Oklahoma and the Children's Hospital at Oklahoma University Medical Center.

Jarvis seeks to positively empower patients and their families, so that, together with the physician, they are working as a team. To illustrate the idea of the team, he uses the image of a three-legged stool: "If one leg is missing, the stool falls down."

Jarvis' own ethnicity is Mohawk and French Canadian, and he reminds himself that "some indigenous Americans believe a disease is what the Great Spirit has sent to make you a better person; bear



UNDERSTANDING THAT A SICK INDIVIDUAL EXISTS WITHIN THE COMMUNITY IMPLIES THAT THE COMMUNITY IS SICK AND THUS SHARES BOTH THE SOCIAL RESPONSIBILITY AND THE POWER TO HELP HEAL.



through it and learn from it, rather than get rid of it."

When treating members of the Native American population, Jarvis recognizes other intrinsic psychological and spiritual components as well: "The body can't be well if the spirit is not; if you don't understand that, you can't really set about the process of healing, for human life is not one-dimensional," he says.

As always, seeing the world through the eyes of the patient is necessary, a lesson he learned when treating an initially uncooperative American Indian female adolescent. He recounts that he sat down and introduced himself to her, inquired about her family, asked open-ended questions—"as medicine men would do"—and allowed her to tell her story as the family listened.

"In traditional healing methods, the patient's narrative is a big part of the envelope that healing has to wrap around," Jarvis says. "The conversation ritual is a traditional way for Native Americans to engage one another—it is an acknowledgment of the patient's humanity."

"Understanding that a sick individual exists within the community implies that the community is sick and thus shares both the social responsibility and the power to help heal," he explains.

For Oakland, Calif., resident Helen Adams Franklin, the power of community manifests itself admirably in the front yard and inside the house she shares with her husband. "The



QUIZ: Know Yourself

Your upbringing, background, and culture shape the attitudes you have toward physicians and the healthcare system as a whole. Take a moment to review these questions and reflect on how your beliefs and viewpoints might affect your health decisions.

- Were you raised to trust authority or question it?
- When an authority figure (like a physician) tells you to do something, are you likely to follow instructions carefully?
- Have you (and your family) had mostly positive experiences with physicians? Or do you second-guess their decisions?
- Do you feel comfortable asking your physicians tough or uncomfortable questions?
- Do you ever feel like there is a language barrier between you and your doctor? Do you have trouble expressing concerns? Or trouble understanding complex medical instructions?
- Have you ever felt like you could use the help of a translator?
- Do you believe that complementary or alternative medical treatments can be just as useful as standard Western medical care?
- Do you always tell your doctor about complementary or alternative medical treatments you use?
- Do you take yourself—and your worries—seriously? Do you take your symptoms seriously?
- Do you have strong views about the roles that men and women play in a family? Does your health ever suffer because you take on too many responsibilities at home or with your family?
- What role does religion play in your life? Do you think religion plays a role in your health?

There are no right or wrong answers to these questions. But thinking about these topics could change the way you think about your healthcare. For example, if you don't feel comfortable questioning authority, maybe the next time you meet with your doctor it would be helpful to bring a friend or family member who could speak up on your behalf. Or maybe you'll decide you need the help of a translator. In the end, the most important thing is to have honest and open relationships with the people who are providing your healthcare. Your mind, body, and spirit will all benefit!

family comes over to cook and clean up, neighbors look after my flowers, and my husband, Teddy—he's 'Driving Miss Daisy,' taking me places and allowing me to still do my work," she says.

Adams Franklin, 54, is African American and credits her culture with keeping her spiritually centered. "God, grace, and mercy have been paramount, and I'm surrounded by love from family and friends. Women of color are very supportive of one another, a trait of people who have tapped into their spirits."

She adds proudly that both her sons are "phenomenal young men," and she tells the story of how, after her lupus diagnosis, one of them said to her, "Mom, you need to lean into this and flow."

She says, "I came out with a different

attitude and started my own business, a natural skin care line with products for people like me."

Her inner peace has calmed her stress as well, and now, she says, "I laugh all the time, and my joy is waking up in the morning. I'm uplifted." The vivacious Adams Franklin was especially "jazzed" at sharing her story with *Lupus Now*. "In my mind, I've gone from a blurb in a magazine to being Oprah!"

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Want to Learn More? Read "Ten Guidelines for Culturally and Linguistically Appropriate Care" in the Healthcare Professionals section on page 34.