Your Family & Your Health

Genes and Stress
Your Health History
Kids: Beyond Ritalin
Fitness for Families

With Harvard Medical School
When Cultures Clash

BY ANNE UNDERWOOD
AND JERRY ADLER

UNGU, MANDARIN, HAITIAN
Creole ... By the thousands each
week, they pass through the
doors of Elmhurst Hospital in
Queens, the borough of New
York City that contains Kennedy airport and
is home to perhaps a greater diversity of
foreign-born immigrants than any compar-
able community in the nation or the world.

Spanish, Korean, Albanian ...

A broken bone is the same in any lan-
guage, but not so diabetes or hyperten-
sion—abstractions for which many people
do not have words. The very concept of or-
ganic illness varies from culture to culture.
If you were brought up to believe that your
symptoms arise from sorcery or from
something you did in a previous life, you
might not grasp the necessity for a course
of chemotherapy whose most immediate
and obvious effect will be to make you feel
a hundred times worse. And if well-
educated Americans sometimes find it
hard to keep track of the complicated regi-
men of medications for, say, heart failure
and diabetes together, it surely is no easier
for a Pashto speaker relying on her grand-
son to explain how to measure her blood
sugar. There are barriers to communica-
tion even among people who speak the
same language, like a white AIDS special-
ist and the African-American patient who
knows that the only people he sees dying of
the disease are black.

The languages were different—Polish,
Health for Life

Yiddish or Italian—but even a century ago, poor immigrant patients and upper-middle-class physicians faced each other suspiciously across a vast cultural gap. But probably never in our history has this country had to absorb so many newcomers from such a diversity of cultures, and medicine, which touches so intimately on their lives, has never been more specialized and technological. “Hmong [a Laotian ethnic group with a pastoral culture] will smile and nod when they’re with the doctor, but they have no intention of taking the pills,” says Sa Vang, a fourth-year medical student at the University of California, Davis, whose parents came to the United States in 1979. “My grandmother would only take her blood-pressure medication when she had a headache.” Vang has seen this happen many times in her community: patients who take their pills in response to a specific symptom, which may or may not be related to the condition the drugs are supposed to treat. The patient doesn’t want to offend the doctor, so he says he’s been taking his medicine; the condition hasn’t improved, so the doctor increases the dosage, to the point where the patient starts to experience unwanted side effects. The result: “Patients think the doctors don’t know what they’re doing.”

The best-documented case of such misunderstandings involved Lia Lee, the daughter of a Hmong family in Merced County, Calif., in the late 1980s. When she was 3 months old, she fainted on hearing the sound of a door slamming. Doctors assumed the seizures she suffered after that were from epilepsy, but her parents provided their own diagnosis, the temporary disappearance of her soul out of her body, a condition whose name translates as “the spirit catches you and you fall down” (which was the title of an excellent book by Anne Fadiman on Lia’s case). Modern medicine could have controlled her epilepsy is unknown; what Fadiman found was that her highly competent and dedicated doctors prescribed more than a dozen different drugs in various dosages and combinations that changed 23 times in four years. Her well-meaning parents, illiterate from poor communication with their doctors. Minorities often carry a burden of suspicion with them into the examination room, as shown in a RAND Corp study this year; 53 percent of African-Americans surveyed agreed that there is a drug to cure AIDS, but poor people aren’t being told about it, and nearly one in six believed that AIDS was created by government scientists to control the black population. Lead researcher Laura Bogart noted that men who held those beliefs were significantly less likely to use condoms.

“When I was in medical school, there was lots of talk about [racial] disparities in health care, but it focused on access,” says Dr. Maren Grainger-Monsen, director of the Bioethics in Film Program at Stanford. “Then we learned that minorities with equal insurance and access still had drastically worse outcomes in cardiac surgery and lung cancer.” Grainger-Monsen believes the “shocking” disparity can be attributed, in large part, to cultural differences and failures of communication, which afflict minorities. Her new film, “Hold Your Breath,” recounts the case of Mohammad Kochi, an Afghan immigrant who was treated in California for stomach cancer. After his surgery, doctors recommended chemotherapy, but Kochi refused to undergo an unpleasant treatment that might not work. His real objection emerged much later: his doctor had prescribed a continuous intravenous infusion of chemotherapy, which would have minimized the side effects. But Kochi was a devout Muslim who prayed five times a day and could not let foreign fluids enter his body after he had cleansed himself for prayer—a prohibition that he believed extended to an IV drip. He never knew there were other ways to receive chemotherapy—and by the time this got straightened out, it was too late to help.

A trained medical interpreter might have gotten to the root of Kochi’s problem sooner, but he had relied on one of his daughters, who had her own ideas about which information her father should receive. When his doctor told him that he still had cancer after the surgery, she refused to translate that information, fearing it would upset him. Dr. Joseph Betancourt, director of multicultural education at Massachusetts General Hospital, recalls how as a 7-year-old he was asked to serve as the intermediary.
between a doctor and his Spanish-speaking grandmother from Puerto Rico. Simple ignorance of medical terms was compounded by embarrassment; his grandmother was suffering from uterine cancer. “We still see kids acting as the cultural brokers for their families,” says Betancourt, “but it’s no way to run a hospital.”

The medical profession has its own traditions, of course, and humility did not always rank high among them. But physicians increasingly realize that, simple human dignity aside, respecting patients’ cultural beliefs can avoid tragedies like Lia Lee’s. Fadiman’s book on the case is now assigned in many medical schools; at Yale, incoming students discuss it on the very first day of class. And more than 100 medical programs use the saga of Kochi to help teach “cultural competence.” As Sa Vang shows by her own example, many of the problems will lessen as immigrants assimilate. It would be unthinkable for her to do as her parents did, when they sacrificed goats and chickens to cure her grandmother. She knows that disease is not caused by evil spirits snatching the soul out of the body. Her husband doesn’t really believe that either, but neither does he let their two young sons attend funerals, where the evil spirits are especially active. And Sa Vang, the medical student, doesn’t object.

Hereditry and Health
INSIGHTS FROM HARVARD MEDICAL SCHOOL

Tracking Family History

BY HOWARD LEWINE, M.D.

Elevated cholesterol is always a cause for concern, but 48-year-old Mary Carleton had special reason to worry when her LDL started inching up five years ago. Her parents had both developed coronary-artery disease at young ages, and her uncle and grandfather had died of heart attacks before the age of 50. As a practicing nurse, Carleton knew that her family history placed her at special risk, but she also knew how to offset it. When her LDL level hit 166 milligrams per deciliter despite a good diet, she and her physician agreed that she should start taking a statin drug—a step that someone with a different genealogy could have safely postponed. Today, thanks to her vigilance, Carleton is in good cardiovascular health—and her kids are taking early steps (extra exercise, lots of fruits and vegetables) to counter the family legacy.

Each of us inherits a unique set of health risks from our ancestors. For some diseases, family history is defined by a single scrap of DNA. Anyone cursed with the gene for Huntington’s disease will eventually suffer the symptoms, but hereditary risks are rarely so straightforward. Most medical conditions involve multiple genes, which get passed along in different combinations. As a general rule, having a first-degree relative with heart disease, asthma, osteoporosis or type 2 diabetes doubles your own risk. When two or more cases occur in the same immediate family, the odds increase by four fold or more. The same pattern holds for cancers of the breast, colon and prostate. Yet none of these conditions is inevitable, even in people at high risk. With a detailed knowledge of your family medical history, you can often take the steps needed to protect yourself.

How much information do you need? “You want to have basic medical facts about your parents, siblings, grandparents, aunts, uncles and first cousins,” says Anu Chittenden, a genetic coun-
selor at Boston’s Dana-Farber Cancer Institute. Chittenden suggests recording each family member’s major medical diagnoses and noting the age of onset for each one. Carleton was intimately familiar with her relatives’ heart conditions, but the facts aren’t always so obvious. In the past, parents often hid medical problems from their children, and families rarely questioned doctors on the specifics when someone died. Even when that information was shared, it was often forgotten. If you want to know how a relative died, Chit-
tenden recommends obtaining a copy of the death certificate, a public document. With proper documentation, next of kin can obtain any of the deceased’s medical records.

If you discover that a serious health problem runs in your family, don’t despair. By eating well, exercising and monitoring your intake of essential nutrients and vitamins, you can offset and sometimes even neutralize your genetic susceptibilities. This is especially true for atherosclerosis, type 2 diabetes and osteoporosis. We don’t have as much evidence for cancer prevention, but family history can help guide decisions about screening and early detection. For example, if you have two or more first-degree relatives with colon cancer or polyps, you should have your first colonoscopy at the age of 40 or 10 years earlier than the youngest relative’s initial diagnosis, whichever comes first. A woman with a strong family history of breast cancer should pursue earlier and more frequent mammograms. Some high-risk women also benefit from tests for BRCA 1 and 2, genetic mutations that raise the risk of breast and ovarian cancer. And though experts still debate whether all men should undergo PSA screening for prostate cancer, men with a strong family history should have yearly PSA testing starting before the age of 50.

With all these diseases that run in families, the challenge is to find out whether they run in yours.

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