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UNFOCUSED RESEARCH IN U.S.

By Jessica M. Scully

Special to the Mercury News

Chi Guo knew that the hepatitis B he contracted as a young child in Taiwan could put him at risk for liver problems. He had brought up his concern during regular checkups with his doctor during his 12 years in the United States.

``I mentioned to several doctors that I had the hepatitis B virus. They did an annual physical exam, and sent me in for a liver function test,'' said the 38-year-old San Jose resident. ``They said I was perfectly healthy.''

But those standard tests missed something critical -- a large tumor on Guo's liver. It showed up only after a new doctor, aware that hepatitis B can lead to liver cancer at much earlier ages than normal in Asians, ordered an ultrasound about a year ago. Guo has since had 75 percent of his liver removed.

Such cases, say doctors, researchers and Asian health advocates, point to a growing problem. Scientists and patients alike say they face a serious lack of health information on Asian-Americans. Much of the standard information on diseases and treatments is based on research done on white Americans, whose health issues can be very different from those of Asian descent.

Broadening the problem is the large number of ethnicities and nationalities that fall within the ``Asian'' category. People living in countries from Korea to Vietnam to India view themselves as very distinct from one another, and often have different health problems. But in the United States, they are often lumped together -- including in medical studies done on Asian-Americans.

With groups such as whites and African-Americans, ``we have a much better idea of the leading health problems and how they have changed over time,'' said Dr. William Satariano, a specialist on aging at the University of California-Berkeley's School of Public Health. ``We simply don't have that information about Asian-American groups.''

Reasons for the lack of information on Asian health are complex. Because Americans of Asian descent make up about 4 percent of the overall U.S. population, and about 12 percent of California's population, there are relatively few people from any given culture to study. Language and cultural differences are other barriers.

Some experts point to misperceptions that Asians are a model minority who don't need services, or that Asians are alike enough to be lumped together in studies.

They argue that Asian groups can differ dramatically in income, lifestyle, diet, genetics and other factors that affect health risks. Once different Asian groups are examined separately, they say, unexpectedly high disease rates often appear.

Little guidance

The lack of information means health care providers don't have a road map to help them in diagnosing Asian-American patients.

Physicians ``start looking for things on the basis of age, family history and risk factors,'' said Dr. Moon Chen, principal investigator at the Asian American Network for Cancer Awareness, Research and Training, a collaboration between the National Cancer Institute and Ohio State University.

``If they're not taught something is a problem in Asian-Americans, they're not going to look for it,'' he said.

As with white Americans, cancer, cardiovascular disease and diabetes are common health problems among Asian-Americans. But disease rates can vary among Asian subgroups and between Asians and whites.

For example, while cardiovascular disease is the leading cause of death in most racial and ethnic groups, cancer is the leading cause of death for Asian-American women.

Liver cancer rates in Asian-Americans are dramatically higher than in whites. Liver cancer rates are 13 times higher in Vietnamese-Americans, eight times higher in Korean-Americans and six times higher in Chinese-Americans than rates in white Americans, according to information compiled by the Asian Liver Center at Stanford University.

In Asian-Americans, who can get the disease in their early 30s, hepatitis B in nearly always the cause of liver cancer. But in whites, hepatitis B usually doesn't lead to liver cancer before old age. Hepatitis C is a far more common cause of the cancer in whites, whose livers will virtually always show signs of scarring, or cirrhosis, before cancer.

The reason for the discrepancy is due to how early each group typically gets the disease, according to Dr. Samuel So, director of the Asian Liver Center. Most whites get hepatitis B through sex or through intravenous drug use in their late 20s or early 30s, he said.

But because the virus is endemic to many parts of Asia, immigrants and their children commonly get the disease in utero or in early childhood, he said. That means that most Asians carry the virus decades longer than whites.

So, the doctor who removed Guo's tumor after a colleague at Stanford found it said hepatitis B can do the most damage in Asians when they are children, in the first decade of infection.

Tests fail to catch damage

Often the standard tests for liver damage, liver function tests, won't show a problem in adult Asian-Americans because the damage was done decades ago, So said. Because the liver is behind the ribs, physical examinations won't find a tumor unless it is massive. The only sure ways are to perform an ultrasound or a more detailed liver test, he said.

But So's work isn't common knowledge among other doctors.

``Sometimes they go around teaching young doctors based on the Caucasian facts,'' he said. ``There are a lot of doctors who have the preconception that there is no role for screening'' for liver cancer in patients with hepatitis B.

Liver cancer isn't the only kind of cancer where most medical information is based on whites, according to Dr. Tung Nguyen, an internist at the University of California-San Francisco. Nguyen, part of an organization promoting better health among Vietnamese-Americans, treats elderly patients with chronic diseases.

``If you're interested in looking at the literature and how it pertains to a patient, for Asian-Americans you just don't have it,'' he said about medical literature. ``When you go to the literature, it's almost invariably done on white people. Fifteen years ago, it was almost invariably done on white men.''

Nguyen cited a well-known study on the breast cancer drug tamoxifen. The study, published in the September 1998 issue of the Journal of the National Cancer Institute, found the drug significantly reduced the rates of breast cancer in high-risk women, though the women had an increased risk for uterine cancer.

Only 4 percent of the women in the study were minorities.

Side effects

Nguyen said his patients worry that they will have more side effects from medications than whites, and a few studies have confirmed their fears.

``I can't honestly tell how the medicine will affect them,'' he said of his Asian patients. ``Without that information, oftentimes my patient will say, `I'm not interested.' ''

Diabetes is another disease in which risk factors can differ between whites and Asian groups. Obesity and inactivity are generally considered the biggest risk factors for adult-onset diabetes.

But several studies, including a review in an issue last year of the Journal of Diabetes and its Complications, have noted that while the diabetes rates for Indo-Americans are far higher than for whites, far fewer people of Indian descent are obese than are whites.

Indo-Americans' risks

Dr. Ramani Rangavajhula, a professor of women's health and health management at San Jose State University's department of health science, teaches about diabetes and diabetes risks in her classes. She said the standard current information is a problem for people of Indian descent.

``You look at the risk factors to check off and think, `I'm not in any of the risk categories,' '' she said.

Rangavajhula said theories about the rising diabetes rates in both Indians and Indo-Americans abound. Some think it's due to processed rice, to stress or to Westernized diets. But none of those questions will be answered without more study, she said.

Health experts say there are a variety of reasons why information on these and other health problems in Asian-Americans isn't available. Some say the problem is solely a matter of statistics. Because Asian immigrants come from more than 60 countries, there are statistically few people that fit into the requirements of a particular study.

Language is another barrier, especially for recent immigrants. Asian immigrants speak a wide variety of languages. Cultural differences and different views about health care can be other barriers, especially for recent immigrants, according to Dr. Candice Wong, an epidemiologist at UCSF.

In a study Wong conducted in the Central Valley on approximately 200 Hmong families with high blood pressure, she found that many were suspicious of Western medicine or thought environmental problems caused their high blood pressure.

``They believe that modern medicine is too strong for them, that it may cause more side effects,'' she said. ``They believe that blood pressure is caused by their blood, or that it's the food they eat, or the pesticides in the food since coming to the U.S. causes their diseases.''

Others think part of the reason for the lack of studies is due to misperceptions or stereotypes about Asian-Americans.

``I think it's connected with the mythology around Asians not being a needy group, being the model minority, not being in need of services,'' said Carmelita Tursi, associate director of diversity programs at the American Society on Aging.

Many people think of Asians as a monolithic group, she said. Some generalize lifestyle factors like diet, assuming that any Asian diet is healthier than the diets of other ethnic and racial groups. But that's not necessarily the case.

``The Japanese diet is really good as far as being healthy, but the Filipino diet isn't necessarily healthy with all of its fried food,'' Tursi said.

Call for more studies

Government organizations that deal with minority health issues agree there's a problem.

Research on Asians ``has improved over the last couple of decades, but it's certainly not where we would like it to be. It's certainly not complete and comprehensive,'' said Dr. Olivia Carter-Pokras, head of data and policy at the U.S. Department of Health and Human Services' Office of Minority Health.

Pokras said larger studies and national data need to be supplemented with studies targeting different racial and ethnic subgroups. ``What we do have indicates that there are important differences by subgroup, and there are important differences by generational status,'' she said.

Some experts say that although there is still much to be done, during the last few years they've started to see more attention paid to the health of Asian-Americans. They're seeing more studies being funded on Asian-Americans, and more partnerships to address Asian-American health.

In April 2000, the National Cancer Institute and Ohio State University became partners to create Chen's group, the Asian American Network for Cancer Awareness, Research and Training. The group now operates programs in San Francisco, Los Angeles, Boston, New York and Seattle.

The National Center on Minority Health and Health Disparities, an agency created nine years ago to deal with problems like these, plans to focus on spreading culturally appropriate health information, to promote a more diverse group of researchers and to promote more research, according to Dr. John Ruffin, the center's director.

In cities with a large Asian-American population, community groups have banded together to provide services. Yu-Ai Kai, a group in San Jose, helps primarily elderly Asian-Americans with health information, nutrition and medical referrals. Other organizations in the South Bay operate awareness and advocacy programs. The Indo-American Community Service Center in Santa Clara runs periodic diabetes awareness classes.

But researchers and advocates say there is more to be done.

They want to ensure that agencies continue to collect information on race and ethnicity. Asian health advocates say they want to see Asians included in studies more often. Not every study has to include every ethnic group, they say, but more targeted studies are needed to truly understand health problems.

Nguyen, the San Francisco physician, said he thinks many people assume making an extra effort to include Asians is too difficult.

``We have to decide as a society, that's not an acceptable decision,'' he said. ``If a study addresses a health issue that potentially involves Asians, Asians should be included in the study population. I'm not saying that every single study needs to be including every subgroup. I'd just be happy that there's any Asian representation at all, as long as you specify which group you're studying.''