

Unprotected People #49

Hepatitis B

Young doctor learns he has liver cancer too late

Recounting a young doctor's death from hepatitis B-related liver cancer, the story is a tragic example of the consequence of inadequate medical attention to people with chronic hepatitis B. A lack of information about how to appropriately screen patients with chronic hepatitis B for liver cancer puts many lives in jeopardy. For information about the management of patients with hepatitis B, consult a liver specialist experienced in the treatment of viral hepatitis.

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From our table at a sidewalk cafe in August 2000, my partner Mark and I took turns pointing out things that made us smile: a young couple pushing a baby stroller, a rambunctious puppy tugging at his leash, an elderly couple holding hands. Our mood was sublime, like the day, as we headed to an open-air jazz festival near San Francisco with a blanket for napping on a grassy slope.

Until a sharp stomach pain made Mark wince and double over. Was it the ulcer he feared? At 30, Mark was a young doctor saddled with debt and the challenge of building a career after eight sleepless years of medical school and training. A life with dogs and kids was only a wistful thought. He crawled into the back seat of the car, cursing and writhing, as I sped him to the emergency room where he worked.

Mark didn't have an ulcer. An ultrasound of his abdomen showed an ominously patchy liver. A biopsy confirmed the worst: cancer. His liver was riddled with so many out-of-control cancerous lesions that neither surgery nor transplant was possible. Chemotherapy would only slow his inevitable, insufferable demise 14 months later. But the question remained,

how did such an otherwise perfectly healthy young man, who had a gym-toned body and never drank, end up with the organ of a hard-living alcoholic twice his age? The answer was chronic hepatitis B, a virus that can silently harbor in a healthy liver for decades before unleashing its destructive power.

Mark knew about his hepatitis. He discovered it from blood tests required by his medical internship. But experts at the prestigious Midwestern hospital where Mark did his residency told the 26-year-old not to worry. He was a "healthy" carrier, they said. His symptom-free, nonactive kind of hepatitis wouldn't have to be monitored for liver cancer until he was in his 50s or 60s. Good advice, if Mark were not an Asian man. (Editor's note: No hepatitis B carrier, regardless of ethnicity, should wait until age 50 or 60 for liver cancer screening. Screening people with chronic hepatitis B infection for liver cancer should generally be done every 6-12 months and should start at the time of hepatitis B diagnosis. Consult a liver specialist experienced in the treatment of viral hepatitis for appropriate monitoring guidelines.) Had he or his doctors been trained to know that Asians are at accelerated risk because they are typically infected as children, he would have immediately gotten regular ultrasounds and blood tests to catch the cancer that killed him at 31.

Soon after his diagnosis, Mark was shocked to see a sign on a city bus advertising Stanford University's "Jade Ribbon Campaign," a program to raise awareness of his disease. Was there really a chronic hepatitis B-fueled epidemic of liver cancer among young Asian-Americans? Are Asians really 10 times more likely to die from liver cancer than a white person? How come he hadn't heard this before? He was, after all, an Asian doctor practicing in a region with a population that is nearly one-third Asian. But as a victim among healers, what happened to Mark pre-

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cisely illustrates the problem, says Dr. Samuel So, director of Stanford's Asian Liver Center. "Only in a medical world that relies almost entirely on a Caucasian model for diagnosis and treatment could such a great health disparity exist," says So, who lectures on ethnicity and medicine at Stanford in addition to his surgical and research duties.

Liver cancer is rampant in Asia. The main culprit is chronic hepatitis B, a virus transmitted by blood or semen. Exposure to it at childbirth is the real problem, because that's when the risk of chronic or life-long infection is greatest.

Unsanitary living and medical conditions throughout Asia have fueled hepatitis B infection rates there, as large percentages of mothers unknowingly pass the virus to their kids. Since it can take 30 years to manifest, all adult children of Asian immigrants—even those born in the United States—are at risk. Especially sons. The virus may infect the sexes equally, but it triggers deadly cancer more often in men.

Mark was born and raised in suburban Chicago by Chinese parents who had lived in the Philippines. While many newborns are vaccinated for viruses such as hepatitis in the U.S. today, an entire generation now entering adulthood was not. Stanford's Dr. So estimates that up to 10 percent of adult Asian-Americans have chronic hepatitis B and do not know it. Of those, a quarter will die from liver cancer or failure. That is an alarming number, since the Asian-

American population is one of the country's fastest-growing minority groups. In California, 30 percent of San Francisco and 12 percent of Los Angeles is Asian. How many unaware young Asian men will double over in pain one day like Mark did?

Before Mark died last October, he became a spokesperson for the Jade Ribbon Campaign (<http://liver.stanford.edu>), urging all Asians to check their hepatitis status. Confronting his own mortality wasn't easy for him. "It's scary to think of your life in months, instead of years," he told me as his death approached, our dreams of that day at the sidewalk cafe shattered. I am still feeling the anger and despair that can engulf you when the person you love is taken away. It hurts most because Mark Steven Lim was such a vibrant and vital force to his family, friends, and patients. As a talented doctor and consummate human being, he had so much potential to do good. Yet his life was so short, and his death so horrible. In the end, the most he could do was hope his words might inspire his medical colleagues to offer—and his Asian peers to seek—the information that can save thousands like him from his fate. If only they listen.