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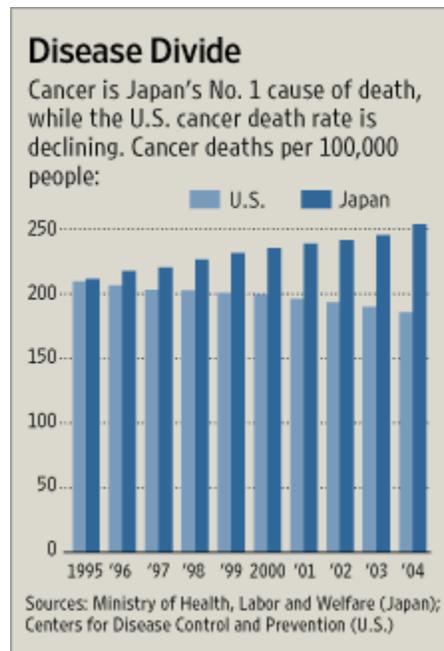
Japan's 'Cancer Refugees' Demand More Options

Patients Decry System That's Frugal, Universal But Restricts Choices

 By PETER LANDERS
 January 11, 2007; Page A1

TOKYO -- With the prime minister looking on, a legislator named Takashi Yamamoto stood before Japan's parliament last May and told his colleagues that he had cancer. Then he denounced the nation's standard of cancer care. "Even when there are treatments, people are being told they will never get better," he said. "These abandoned cancer refugees are roaming the Japanese archipelago."

The speech galvanized the parliament, which had been dawdling over a bill that called for more cancer specialists and a permanent role for patients in policy making. Within four weeks, the bill became law. ([Read translated excerpts of Mr. Yamamoto's speech.](#)¹)



It was a signal victory for a spreading movement in Japan among patients who want American-style care and drugs for cancer. But the idea of becoming more like the U.S. raises alarms among policy makers. In Japan, the government guarantees that everyone has health-insurance coverage and it pays most of the bills.

Masaharu Nakajima, until recently director general of the Health Bureau at the Ministry of Health, Labor and Welfare, says Japan already offers excellent cancer care. With a huge national debt and corporations worried about higher taxes, Japan can't afford to throw money into treatments and training that offer little hope of significantly extending lifespans, he says.

"If we keep going like this, Japan is going to be crushed under medical expenses," says Dr. Nakajima, a surgeon who used to treat cancer patients before joining the ministry. Referring to the demand for more specialists, he says: "America did too much of this and that's why their

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medical costs have grown."

The debate in Japan raises the question of where nations should draw the line when modern medicine offers almost unlimited ways to spend money. In the U.S., both private insurers and public programs such as Medicare take a relatively generous view, usually paying for treatments that offer some hope of helping the patient. Japan is far more tightfisted. Spending on health in Japan each year is roughly half the level of U.S. spending, adjusting for the size of each country's economy.

Health spending in Japan is even lower than in most Western European countries and Canada. Yet if that's hurting people, it's hard to find evidence in the statistics. Japan has the world's highest life expectancy for women (men are No. 4) and one of the world's lowest infant-mortality rates.

WHAT MR. YAMAMOTO SAID



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"Even when there are treatments, people are being told they will never get better. These abandoned cancer refugees are roaming the Japanese archipelago."

-- *Read excerpts*³ of the May 22, 2006, speech by Takashi Yamamoto

Many countries are grappling with how to improve care while containing costs. In Japan, debate about the system has focused on cancer, by far the nation's leading killer. The Internet has helped break down patients' isolation from information about their disease and supplied data on foreign treatments. Cancer activists believe inadequate treatment on occasion cuts short the lives of Japanese. Some focus their ire on the

very notion that mortality numbers can measure the value a health-care system delivers.

Hidesuke Hashimoto, who has been treated for lung cancer and leads a patients' group, says Japanese bureaucrats, unlike Americans, fail to recognize the value of pursuing all possible avenues of treatment when a person is seriously ill. "Our rights as individuals aren't being recognized," says Mr. Hashimoto, a 68-year-old retired math teacher. "We have the right to live." More government spending on health care, he suggests, would be a small price to pay for promoting democracy and the rights enshrined in Japan's U.S.-written constitution. Article 25 says all people are entitled to a minimum standard of "wholesome and cultured living."

Cancer accounted for 326,000 deaths among Japanese in 2005, or 30% of the total -- more than heart attacks and strokes combined. The rate of cancer deaths per 100,000 population continues to rise slightly, in contrast to a slight decline in the U.S. Whether poor care has something to do with that is a matter of debate. Demographics and lifestyles also may play a role: Japan is a rapidly aging nation where nearly half of men smoke, while obesity and heart disease are relatively uncommon. Those factors tend to increase the proportion of deaths caused by cancer.

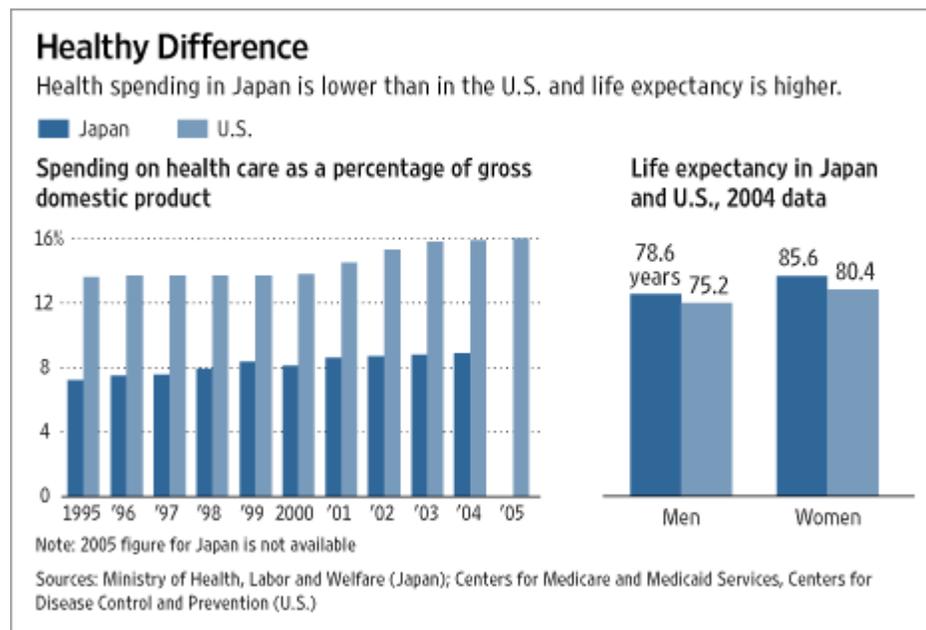
Since Japan introduced universal health-insurance coverage in the late 1950s and early 1960s, its policy has focused on ensuring a minimum standard of care for all. People are required to pay a monthly health-insurance fee. Large companies must also pay health-insurance fees, but the rules of the game -- what is covered, how much doctors get paid -- are mainly set by the central government in Tokyo.

After World War II, Japan achieved an improvement in life expectancy just as spectacular as its rise to become the world's second-largest economy. Japanese women have been the longest-lived in the world since 1985, according to the health ministry.

Takashi Yamamoto

Meanwhile, the government's frugality has helped keep medical costs at a minimum. The restrictions aren't like those in England, where the government employs most of the doctors. Japan is the largest example of a "third way" medical system, also common in continental Europe, that combines universal health insurance with private doctors.

Japan saves by requiring less training of doctors and paying them less. Aspiring doctors typically go to medical school straight out of high school and become M.D.'s in just six years, compared with eight years of post-high-school education in the U.S. Until 2004, Japanese doctors could go straight into practice without any internship. (Now they must serve as interns for at least two years.) The average doctor's annual income is just over \$100,000, compared with about \$200,000 in the U.S.



Doctors say they have little time for patients. Because people in Japan are generally free to visit any doctor they like, the experience of going to a doctor who's popular is often summed up as "a three-hour wait for a three-minute visit." Health spending in Japan is about 9% of gross domestic product, versus 16% in the U.S.

The frugality has extended to cancer care. More than in the U.S., surgeons take a major role, including deciding on drug treatment -- typically the province of a specialized cancer doctor in the U.S. Through the late 1990s, the concept of a second opinion was virtually unknown. Today, Japanese people borrow the English words and talk about getting a "sekando opinion."

Until recently, cancer patients often did little to buck the system for a simple reason: Many weren't told they had the disease. It was common for patients to place complete trust in their doctor and refrain from asking why they were receiving an operation or medicine. Family members usually heard the true diagnosis, but they often felt it was cruel to burden the patient with that information.

Shintaro Abe, a politician and father of Japan's prime minister, Shinzo Abe, was widely known to have cancer for two years before his death in 1991. But the elder Mr. Abe was kept in the dark about his pancreatic tumor until his final two months, when he suspected the truth, according to his widow's memoirs.

Mr. Hashimoto, the former math teacher, says he was first diagnosed with liver cancer in 1990 and underwent surgery to remove a tumor, but his family kept the diagnosis from him. He says he was shocked when his son told him in 1999 that he had cancer and it had spread to his lungs. The son

wanted Mr. Hashimoto, who lives near Kobe, to travel to Tokyo to get chemotherapy at the National Cancer Center and realized it was no longer possible to hide the diagnosis.

Unlike most Japanese patients, Mr. Hashimoto dived into studying his disease, scouring books and the Internet. "I was told twice that there were no more treatments for me," he says, but each time, he moved to a new hospital for experimental treatment, sometimes paying out of pocket for procedures not covered by the state. He joined and eventually led a patients' group.



**Hidesuke
Hashimoto**

With his activism, Mr. Hashimoto was joining a growing movement. Around the turn of the century, new chemotherapy drugs and the spread of the Internet spawned a class of activist cancer patients. The government was quick to approve a handful of drugs that clearly could extend lives -- in particular **Novartis** AG's Gleevec, which was approved in Japan the same year as the U.S. But other drugs with more marginal benefits languished for years. Sometimes foreign drug makers were slow to seek approval in Japan, fearing the government-set price would be too low to make it worth their while.

HOW MUCH FOR HEALTH?

The Issue: At a time when medicine offers countless ways to spend money, where should a nation draw the line?



The News: In Japan, which spends far less than the U.S. does on health care, some cancer patients demand access to more drugs and survival options.

What's at Stake: Patient choices and spending levels in Japan, as well as drug companies' market penetration.

To desperate patients, it was infuriating that the government didn't rush every potential life-saver to market, however slim its benefits might be. One example is Eloxatin, a drug that has been shown to extend lives by a few months, on average, in patients with recurring colorectal tumors. After patients held street rallies passing out fliers and repeatedly visited parliament, Japan approved the drug in 2005, nearly three years after the U.S.

Other drugs have yet to make it to Japan. The government is reviewing Avastin, approved in the U.S. in February 2004. The **Genentech** Inc. drug also can extend lives by several months on average but costs tens of thousands of dollars a year.

A movement for more drugs and better care culminated in May 2005 when 2,000 patients and family members packed a hall in Osaka for the first national convention of cancer patients. One of the organizers, Shoichi Miura, was a doctor and himself a cancer patient. In his speech, he summoned up a common image here: the "gan nanmin," or cancer refugee. "While Japan has become economically prosperous, cancer patients are in the same position as refugees who wander in search of food, water and someone who can help," said Dr. Miura, who died seven months later.

THE HEALTH OF NATIONS



See data from the Organization for Economic Cooperation and Development comparing **health spending and outcomes**⁴ in the U.S., Western Europe, Japan and selected other countries. (Or read a [Kaiser Family Foundation summary](#)⁵.)

Also, the World Health Organization's **World Health**

Japan's public-television network, NHK, added to the chorus with a two-night prime-time documentary that portrayed Japan as far behind the U.S. in cancer care. NHK introduced the nationwide audience to a hospital in Texarkana, Texas, and showed a meeting in which 25 doctors, nurses and other specialists discussed cancer patients' care. It contrasted that with Japan, where a single doctor, with minimal consultation, might make a

Report⁶ holds health data on the 192 U.N. member nations.

diagnosis, decide treatment and carry it out.

The public pressure has had an impact. Last April, for the first time a medical society designated 47 doctors who had passed rigorous tests as certified oncologists, cancer specialists qualified to administer chemotherapy drugs. The U.S. has had a similar process since 1973, overseen by the American Board of Internal Medicine, and today thousands of oncologists are certified by the board.

The law passed by parliament last June doesn't call for immediate new spending, but it creates targets and committees that will force the health ministry to do more, says Mr. Yamamoto, the legislator whose speech spurred the law's passage. "Cancer patients are becoming informed and beginning to act. It is late compared to America," he says.

Mr. Yamamoto says Japan should be ready to raise taxes to finance more generous care for cancer patients and others. He himself has gone to a maverick doctor who charges patients \$420 out of pocket for a consultation and believes in aggressive treatment.

But government leaders show little willingness to fund a big expansion in health care. The government is grappling with a huge budget deficit left over from the 1990s.

The health ministry has slashed doctor reimbursements and raised co-payments for patients. Many people must pay 30% of their doctor bills, in addition to their regular health-insurance fees, and the maximum monthly out-of-pocket cost went up on Oct. 1 to 80,100 yen (\$670) from 72,300 yen. Meanwhile, the government cut doctors' average reimbursement by 1.36% last year following a similar cut in 2002.

That infuriates doctors. "It's been one cutback after another," says Toshio Nakagawa, a neurosurgeon who serves on the board of the Japan Medical Association. "This time I think they've gone too far."

Dr. Nakajima, the recently retired health ministry official, says policy makers must also worry about the competitiveness of Japanese companies. "Executives want to keep costs down," he says.

Dr. Nakajima says a diligent surgeon who bones up on the latest literature can do just as good a job as a licensed oncologist. He says cancer patients may feel reassured if they see a certificate on their doctor's wall, but that feeling alone isn't worth blowing the government's budget. Says Dr. Nakajima, "It's simply not the case that the survival rate goes up just because somebody got a certification."

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