



FEATURE STORY

The Cost of Living

BY KATHY LATOUR

Cancer patients are living longer, but if radiation was part of their treatment, late effects may be a problem.

Sam LaMonte, MD, knew he had cancer as soon as he touched the lump in his neck. It was 1991, and LaMonte, a head and neck surgeon in Pensacola, Florida, had just stepped down as the president of the Florida division of the American Cancer Society (ACS).

“I told my partners I thought it was cancer, and they were in complete denial,” he recalls. “I wasn’t, because I had been feeling cancer in people’s necks my whole life.”

LaMonte was right. A biopsy revealed cancer; the primary site was found at the base of his tongue. The diagnosis: stage 3 squamous cell head and neck cancer. The treatment: radiation twice a day for eight weeks.

LaMonte, 50, resumed his career three months after he finished treatment. He picked up where he left off with the ACS, joining the national board and becoming the ACS poster boy for survivor issues even after he retired in 2002. Then in 2004, his doctor discovered from an X-ray that LaMonte’s left carotid artery was 100 percent blocked, and the right was 60 percent blocked.

The damage, his doctor said, was the result of radiation that had saved his life 15 years earlier. LaMonte was a stroke waiting to happen. He had never had a symptom.

“I was dumb as a door,” LaMonte says in retrospect. “So was my radiation oncologist about potential late effects from radiation.” Late effects differ from long-term effects, which occur as side effects or complications during treatment and continue into the future. The late effects from treatment may not show up for months or years after treatment ends.



Sam LaMonte, MD, has become a full-time advocate for survivorship issues such as late effects of radiation. Photo by Ginger Moseley.

They may include pulmonary damage, secondary cancers, bone problems, hypothyroidism, fertility issues, intestinal problems, vascular problems such as stroke or heart attack, and neuromuscular and musculoskeletal issues. Of the estimated 13 million survivors in 2011, about 6.5 million received radiation as

part of their treatment. Of those 6.5 million, some could be at risk for late effects.

No central reporting agency has numbers on the prevalence of late effects, their severity and to what degree radiation may have altered a person's risk for a certain effect. Who is potentially at risk for which late effect, when and even if, is determined by a host of individual factors. The message: know the details of your treatment.

Late effects often emerge beyond when survivors may be looking for treatment-related problems, and it's this lack of awareness that sends LaMonte into spasms of frustration. It also keeps him busy trying to educate health care professionals and survivors. He wants patients to know that, while radiation may have saved their lives, it may also have turned them into time bombs.

But more importantly, LaMonte stresses, many late effects can be treated or lessened if survivors are monitored and their primary care physicians know what to look for.

Blessing Versus Curse

The irony in late effects is that patients have to live a long time to experience them. And more cancer patients are doing just that due to early detection, better screening and better treatment options—including radiation. Five-year survival rates for adult cancers and childhood cancers have risen steadily, with adult survivors at 68 percent and childhood survivors at 80 percent.

Michael Stubblefield, MD, an assistant attending physiatrist (rehabilitation physician) in the Rehabilitation Medicine Service at Memorial Sloan-Kettering Cancer Center, specializes in neuromuscular and musculoskeletal complications of cancer. While Stubblefield is quick to point out that many patients, particularly those who received radiation after 1985, do well, he currently treats several hundreds of patients who received radiation recently or 10, 20 or even 40 years ago.

When Stubblefield joined Sloan-Kettering in 2001, he was seeing patients with issues such as shoulder problems after breast surgery. Then, in 2003, a wave of patients began arriving, some from outside New York City, who were suffering from what he defines as the “constellation of disorders” that affect the muscles, spinal cord, nerve roots, local nerves, plexus and muscles as a result of radiation treatment. Most were adult head and neck cancer survivors or adult survivors of childhood Hodgkin lymphoma—two populations that receive radiation as standard treatment.

Their stories were similar, he says. They talked about doctors diagnosing them with fibromyalgia, or being told they were crazy, or being assured their problems couldn't possibly be related to earlier radiation treatment. “The doctors couldn't figure out what was wrong, so there wasn't anything wrong,” Stubblefield says.

Hearing their experiences was an epiphany, he says, and it has been “learn as you go” ever since.

A Sticky Problem

While the new generation of survivors were finding Stubblefield, researchers puzzled over what was happening to healthy tissue when it was radiated. They wanted to stop radiation toxicity to healthy tissue, which would mean more radiation to the cancer and fewer late effects for patients.

Complicating these questions was the fact that not all patients who receive radiation develop late effects. And those who do may not have the same problems.

“Everyone reacts differently and is wired a little differently,” Stubblefield says. “Some people get lung problems and some get heart and some get spinal cord [problems]. We don’t have a good explanation for why people with the same radiation will have a different reaction.”

In their search for the root of the problem, researchers discovered a series of overlapping events in cell function due to radiation injury. Stubblefield says one of the culprits turned out to be an abnormal accumulation of the protein fibrin that was secreted by the damaged cells.

“The fibrin gums up the works,” says Stubblefield. “It deposits inside the blood vessels, outside and even between cells, eventually starving the tissue and causing a slow, insidious wasting.”

The abnormal accumulation of fibrin was responsible for LaMonte’s clogged arteries. Stubblefield explains that, over time, the normal mechanisms that remove fibrin were compromised, leading to its accumulation in places where it shouldn’t be. When this happens in a carotid artery, he says, it can cause the artery to clot off, resulting in a stroke. It’s not known how and why fibrin does what it does, Stubblefield says, and so far, there has been no way to stop it. He can, he says, offer physical therapy and other ways to improve quality of life.

View Illustration : Late Effects of Radiation

Those At Risk

Eileen Gould, an adult survivor of Hodgkin lymphoma, began seeing Stubblefield for a condition dubbed “pencil neck” by long-term survivors because of muscle atrophy. She had physical therapy and was fitted with a cuff to support her neck.

Gould, now the editor of the Sloan-Kettering survivor newsletter, received total nodal radiation in 1978 as a 21-year-old college student after doctors discovered an inoperable grapefruit-sized tumor in her chest. Her radiation treatment was designed by the pioneering team of Saul Rosenberg, MD, and Henry Kaplan, MD, at Stanford University Medical Center and implemented near her family’s home in Ohio.

Not until she married in 1994 and moved to New York City did Gould explore her worsening fatigue. The first cardiologist she visited told her she needed to exercise more, and the second recommended further testing. The third performed an angiogram.

“I had premature coronary artery disease, something they didn’t expect from a 42-year-old, thin, non-smoking woman,” she says. Since then, she has had three heart stents inserted.

Then in 1999, she was diagnosed with early-stage breast cancer, which her doctors attribute to the radiation. Because she could have no more radiation to the chest, three physicians recommended bilateral mastectomy. The fourth physician thought that, with close surveillance, she could tolerate a lumpectomy with wide margins. In what she calls the most difficult decision of her life, Gould chose a lumpectomy. “I had had no control over what happened to me at 21,” she says. “When one doctor said, with close surveillance, I could do a lumpectomy, I did.”



Oeffinger calls Eileen Gould a "classic example" of the patient who had chest radiation for Hodgkin lymphoma or non-Hodgkin lymphoma and later developed breast cancer. Photo by Susan Farley.

Gould found Stubblefield through Kevin Oeffinger, MD, a primary care physician and director of the Sloan-Kettering Adult Long-Term Follow-Up Program.

Oeffinger’s program, which is staffed by four primary care physicians and three nurse practitioners, sees around 500 to 600 patients a year, 130 of whom are new each year; 25 percent come from outside New York City. Like Stubblefield, Oeffinger credits radiation for curing many cancers. At the same time, he concedes that it causes the majority of secondary cancers seen at the clinic.

Gould and Oeffinger met face-to-face in 2005, but they began communicating in 2001 on an Internet message board for survivors. “He was so kind with his time and participation,” Gould says. Then she learned he was moving to Sloan-Kettering, only four blocks from her home. “I felt like I had hit the lottery.”

Oeffinger calls Gould a “classic example” of the patient who had chest radiation for lymphoma and later developed breast cancer. He says that, by age 40 to 45, 13 to 20 percent of women treated with moderate- to high-dose chest radiation for pediatric or young adult cancer will be diagnosed with breast cancer.

Oeffinger also oversees research as part of the Childhood Cancer Survivor Study, a multi-institution effort that, since 1994, has followed some 14,000 five-year survivors of childhood and adolescent cancer diagnosed between 1970 and 1986.

The results of the study have fueled the growing network of survivorship clinics opening around the country that will address the long-term and late effects of cancer treatment.

Some findings from the study, which continue to be reported, identify specific groups of adult survivors of childhood cancer at highest risk for late effects. For example, Oeffinger says, survivors treated with chest radiation, in addition to their risk of cardiac disease and secondary cancers, are at highest risk for pulmonary toxicities, with a four-fold excess risk of lung fibrosis. In addition, nonmelanoma skin cancer represents one of the most frequent subsequent cancers, with 90 percent of patients having received radiation. This is a six-fold increase compared with survivors who did not receive radiation.

Oeffinger says these patients need to know their risk, which begins with knowing the details of their treatment.

Help and Hope

Gould continues to be followed and has made peace with the side effects of her treatment, knowing that she received state-of-the-art treatment at the time. “Here I am 32 years later,” she says. “It’s hard to be angry.”

LaMonte is more frustrated than angry, pointing out that the education isn’t moving as quickly as it needs to. He also challenges today’s patients to educate themselves, to look for the latest radiation techniques, and to demand information on late effects.