What Happens Next?
Managing the Care of Long-Term Cancer Survivors
by Dawn Chalaire

Cancer—as well as many of the treatments for it—can have long-term medical consequences for survivors. With more people than ever surviving cancer today, M. D. Anderson Cancer Center is looking at how to best meet their long-term medical needs. (Continued on next page)
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A 42-year-old woman tells her doctor that she is experiencing chest pains. Echocardiography reveals no abnormalities, and the woman is otherwise healthy, so her doctor suspects that she has heartburn. He prescribes Zantac and tells her to modify her diet. She follows his advice, but the pain continues and worsens. Months later, during a routine follow-up visit, the woman is found to have chronic pericarditis. What went wrong? The physician’s diagnosis was competent, based on the information he had at the time, but he was missing one key fact: 25 years ago, the woman was treated with radiation therapy for Hodgkin’s disease.

The scenario described above isn’t an unusual one. Improvements in the screening, diagnosis, and treatment of cancer mean that more people than ever are surviving the disease. In February, the American Cancer Society reported that the number of annual cancer deaths fell by 369 from 2002 to 2003, the first such decline in more than 70 years, and according to the latest estimate from the National Cancer Institute, there were almost 10 million cancer survivors in the United States in 2001. Today, 64% of adults with cancer will survive at least 5 years, and 75% of children will survive at least 10 years. But amid all the good news is the recognition that there is no comprehensive model for the medical care of cancer survivors. Survivors, and their primary care physicians, often find themselves navigating the complicated terrain of cancer survivorship alone.

Once they reach the 5-year survival mark, most cancer survivors leave the care of their oncologists and return to their primary care physicians—often with a host of potential problems related to the cancer and its treatment. It isn’t that today’s cancer treatments carry greater risks than previous therapies (in fact, many have less toxicity), but people are living longer now, which gives the problems more time to materialize. The side effects of cancer and its treatment can include fatigue, pain, lymphedema, oral problems, weight loss or gain, loss of bladder or bowel control, menopause symptoms, and sexual problems. In addition, cancer surgery can lead to physical limitations such as loss of mobility and weakness; chemotherapy can damage the testes, ovaries, heart, lungs, or bone marrow; and radiation therapy can damage normal tissue and glands in the radiation treatment field.

Most cancer survivors are at risk for recurrence, and many also have an increased risk of developing second cancers. Many types of chemotherapy put patients at higher risk of developing leukemia or the bone marrow failure disease, myelodysplastic syndrome. Survivors of childhood cancers not only have a higher-than-average risk of new cancers as adults but also are five times more likely to have a chronic disease as adults. More than one third of these survivors can expect to have a life-threatening illness or serious chronic disease (i.e., heart problems, dialysis or kidney transplant, paralysis, or mental retardation) by age 45.

In addition to physical problems, cancer survivors face a variety of issues that can affect their quality of life. Many experience depression and live with the ongoing fear of recurrence. Some have cognitive problems such as memory loss or attention problems. Children who have been treated for cancer often find themselves behind in school and may have delays in social development.

For the primary care physician, all of these issues combine to create a very complex patient. Managing the late effects of cancer and its treatment and recommending an appropriate screening regimen require the analysis of interrelated factors that are different for every patient. And to make things even more difficult, patients who have moved or changed primary care doctors since being treated for cancer may not think to tell their new physician about their bout with cancer.

Toward a survivorship care plan

A report published last year from the Institute of Medicine titled From Cancer Patient to Cancer Survivor: Lost in Transition states that there is no clear best practice for caring for patients with a history of cancer and that primary care physicians are seldom given explicit instructions by oncologists. The report recommends that oncologists develop a

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“survivorship care plan” for each cancer survivor that would include information such as the cancer diagnosis, treatment, and potential consequences; recommend the timing and content of follow-up visits; offer tips for staying healthy and preventing recurrences or second cancers; and inform survivors of their legal rights regarding employment and insurance and the availability of psychological and support services.

Rena Sellin, M.D., a professor in the Department of Endocrine Neoplasia and Hormonal Disorders at The University of Texas M. D. Anderson Cancer Center, calls the report “sort of a little Bible” for
Dr. Sellin (l) and Martha Beck, R.N., (r) talk with about making life after cancer as healthy and productive as possible.

those who are interested in improving the care of cancer survivors. “From the perspective of the primary care physician, what this report recommends is that each patient leaving the oncologist’s office be provided with a detailed document that describes the type of cancer, type of treatment, and the follow-up recommended. That would help the primary care physicians know when they are dealing with a routine issue and when the cancer history becomes relevant and they need to consult the cancer center or the oncologist,” said Dr. Sellin, who heads M. D. Anderson’s Life After Cancer Care clinic.

Such a plan, according to Dr. Sellin, should also provide an individualized summary of the patient’s relative risks of recurrence, late effects, and second cancers. “So, for instance, for someone who was treated with radiation therapy and doxorubicin, the chart should note that there is a ‘moderate risk of early cardiac events,’” Dr. Sellin said.

An individualized care plan is necessary because of the many variables involved, including the type of cancer, disease stage, grade, and molecular characteristics; patient characteristics such as age, comorbidities, and overall health; and treatment, including its timing, dosage, and duration. “Many survivors don’t need anything special,” Dr. Sellin said, “but the oncologist should help the patient and the primary care physician determine that.”

If pieces of a patient’s cancer history puzzle are missing or misinterpreted, the risk of recurrence can be overestimated as well as underestimated, possibly leading to unnecessary tests and procedures. Another consequence of putting too much emphasis on a patient’s cancer history is that other important health recommendations, such as diet, exercise, and routine screening tests, may fall by the wayside. “What happens sometimes is that because you had cancer and you’re focused on that, you don’t think the other things are as important,” Dr. Sellin said. In fact, cancer survivors with a low risk of recurrence are often more likely to die of another disease.

Developing a chronic care model

According to Dr. Sellin, the field of oncology has only recently begun to address the issue of “what happens next,” after the 5-year cancer survival threshold, when a patient is considered cured. “This is part of the evolution of the field of cancer care. We are now beginning to develop a model for what happens after the cancer is controlled,” she said. Dr. Sellin chairs a task force charged with determining M. D. Anderson’s role in caring for cancer survivors. “We are comprehensively assessing what a cancer center should be offering to cancer survivors in the coming decades and seriously rethinking what is the right way to do it,” Dr. Sellin said.

One possible model of survivor care would be to coordinate the patient’s follow-up through a clinic like M. D. Anderson’s Life After Cancer Care clinic. Patients would visit the clinic every year or two for screening and to receive any new information about their disease. They could also be referred by their primary care physicians for evaluation of any problems that may be related to their history of cancer. “The clinic screens and evaluates patients and either refers them to the appropriate specialist at M. D. Anderson for further treatment or back to their community physician,” Dr. Sellin said.

Because a clinic specializing in the needs of cancer survivors would only be feasible in large cancer centers, additional models of treatment are needed. One option is to offer outreach programs that support primary care physicians and inform them about issues that may arise in their patients who are cancer survivors.

In Texas, the Physician Oncology Education Program, funded by the Texas Cancer Council, has sponsored a series of physician seminars in various parts of the state focused on cancer survivorship topics, including screening and follow-up care, late effects of cancer, nutrition and physical activity, pain and symptom management, dental care, and end-of-life planning. The program has also produced a series of information modules, including one on cancer survivorship, which will soon be available on the M. D. Anderson Web site. In addition, M. D. Anderson’s Office of Physician Relations is working (Continued on page 4)
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with the Texas Cancer Council to deliver a “cancer toolkit” to local communities to help them develop programs to improve cancer care in their own areas, from screening and prevention to programs related to long-term survivorship.

Lewis Foxhall, M.D., vice president for health policy at M. D. Anderson and chair of the Physician Oncology Education Program’s education subcommittee, is optimistic that these grassroots efforts will make a difference for the growing number of cancer survivors. “I think there’s a real need for building this sort of capacity at the local level to take care of survivors and to do prevention and early detection work,” he said. “Texas has been a leader in developing these kinds of programs, and other states around the country are now following suit.”

“In Texas, there is the realization that primary care physicians are a key part of the system for caring for cancer survivors,” Dr. Sellin added. “We’re working to offer them the specialized information and support they need to do that as this population grows.”

For more information, contact the Life After Cancer Care clinic at (713) 792-2340. Other resources include: Life After Cancer Care at www.mdanderson.org, Texas Cancer Toolkit (texascancer toolkit.org), National Cancer Institute, Office of Cancer Survivorship (www.cancer.gov), Institute of Medicine (www.iom.edu).

IN BRIEF

Study Sheds New Light On Ultraviolet Rays and Melanoma

Researchers at M. D. Anderson Cancer Center have found that the risk of developing melanoma, the most deadly form of skin cancer compared with nonmalignant skin cancers, is only partially associated with exposure to ultraviolet B (UVB) radiation, the rays in sunlight that increase in summer and cause sunburn.

The report in the December 21, 2005 issue of the Journal of the National Cancer Institute indicates that only nonmalignant skin cancers (basal and squamous cell carcinoma) are strongly associated with exposure to UVB radiation. It is well known that in the general population, sun exposure increases a person’s risk of developing squamous cell carcinoma, but the risk of developing basal cell carcinoma increases to a certain point, given exposure to UVB radiation, but does not continue to increase with additional sun exposure.

This does not mean, however, that sunbathing poses a minimal risk for developing melanoma. Researchers say that ultraviolet A (UVA) radiation, the rays in sunlight that reach the deeper layers of skin and are associated with signs of aging, can damage the DNA in melanocytes, the pigment-producing cells that give rise to melanoma.

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Acupuncture, one of the oldest and most commonly used medical procedures in the world, is now being used to ease the side effects of cancer treatment, thanks to research confirming its effectiveness.

What is acupuncture?
Originating in China about 2,500 years ago, acupuncture involves inserting very thin metal needles into a patient's skin. The needles are then manipulated manually or by electrical stimulation. The number and placement of the needles varies according to the type of treatment.

The procedure has been used for the past seven years at M. D. Anderson Cancer Center to relieve cancer therapy-related symptoms, according to Joseph Chiang, M.D., a professor in the Department of Anesthesiology. Acupuncture can help alleviate a wide range of side effects of chemotherapy, radiation, and cancer surgery, including nausea, vomiting, fatigue, pain, dry mouth, insomnia, and headaches, Dr. Chiang said.

Does it work?
Research studies have shown acupuncture to be effective in treating the unpleasant side effects of cancer treatment. The 1997 National Institutes of Health (NIH) Consensus Development Conference concluded that scientific evidence validated acupuncture's effectiveness in controlling chemotherapy-related nausea and vomiting.

Over the past 20 years, acupuncture has become increasingly popular in the United States. The NIH Consensus Development Conference found that acupuncture is widely practiced by thousands of physicians, acupuncturists, and dentists for relief or prevention of pain and for other health conditions. About 8.2 million U.S. adults have used acupuncture, according to the 2002 National Health Interview Survey.

What does acupuncture feel like? Some describe the experience as similar to “a little mosquito bite, a slight numbness, or a feeling of fullness.”

Western medicine has not yet completely explained why acupuncture works, though some studies suggest it may regulate the nervous system, utilizing pain-killing endorphins and immune system cells, or may alter brain chemistry by changing the release of neurotransmitters and neurohormones. Traditional Chinese medicine maintains that disease is caused by disruption of the body's vital energy flow, called Qi, and acupuncture attempts to correct the imbalance of Qi by penetrating the skin at some of the 2,000 acupuncture points on the human body.

What does acupuncture feel like?
Some describe the experience as similar to “a little mosquito bite, a slight numbness, or a feeling of fullness,” Dr. Chiang said. Usually the “very, very fine needles” are left in for about 20 minutes while the acupuncturist twists the needles manually or applies electrical stimulation.

Depending on why acupuncture is being used, the patient may immediately feel the benefit of the treatment or it may take several sessions. For pain relief, sometimes there may be dramatic improvement in one session, while a series of acupuncture treatments are usually required to improve fatigue and insomnia, Dr. Chiang said.

A typical acupuncture regimen involves about ten treatments given over four or five weeks, and after that, patients might come in for less frequent maintenance sessions.

“We don’t want a patient saying this is magic,” Dr. Chiang said. “It’s not magic; it’s another therapy.”

Things to consider
At M. D. Anderson, patients can be referred for onsite acupuncture treatments by their oncologists. The acupuncturists are very careful to screen for pre-existing conditions that might be negatively affected by acupuncture, such as low white blood cell counts or bleeding caused by cancer therapies.

Before cancer patients consider acupuncture, they’re advised to first discuss the subject with their physician to see how it might affect their medical condition. Picking a competent acupuncturist who is licensed and credentialed is also important. Acupuncture is one of the complementary medical treatments most commonly covered by health insurance, but check with your carrier to be sure.

For information about acupuncture, visit www.mdanderson.org/cimer and click on Reviews of Therapies and then Energy Therapies.

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For more information, contact your physician or contact the M. D. Anderson Information Line:
☎ (800) 392-1611, Option 3, within the United States, or
☎ (713) 792-3245 in Houston and outside the United States.
50 Years of OncoLog

by Martha Morrison

For 50 years OncoLog has been bringing community physicians news about M. D. Anderson Cancer Center's latest contributions to the war on cancer. Established in 1956, OncoLog was at first simply called News Letter. The institution's first and only newsletter at the time, it provided a wide range of information, including news about cancer research conducted around the world, conference announcements, grant awards, and profiles of faculty.

Since then, OncoLog has evolved into a monthly publication that arms community physicians with news of the cutting-edge cancer research and innovative medicine practiced at M. D. Anderson. OncoLog shares news about clinical trials, promising translational research in our labs and clinics, and state-of-the-art treatments, and it provides a patient information page about cancer basics that doctors can share with their patients.

In the past 50 years, OncoLog has undergone a name change and several redesigns. It has chronicled M. D. Anderson's advances ranging from the use of the cryostat in diagnosing cancer (1957) to the design of what is now the world's largest ambulatory treatment center for outpatient chemotherapy administration at M. D. Anderson (1988). What began as an informal quarterly newsletter is now a respected professional resource that reaches 33,000 physicians in the United States and around the world.

In 2003, OncoLog became available online and is among the most visited pages on M. D. Anderson's Web site, averaging 840 visits a day, with 13% of site visitors living abroad. Online, it has also become a valuable resource for a wider lay audience looking for more sophisticated, in-depth information about cancer. A Spanish version of the publication is also available online to serve the increasing number of Spanish-speaking physicians.

Under the leadership of a new editorial board steered by Dr. Michael Fisch, medical director of M. D. Anderson's Community Clinical Oncology Program, and Lyle Green, vice-president of Physician Relations, OncoLog will continue to update the medical community on how M. D. Anderson is translating emerging knowledge into improved treatments.

Since 1956, M. D. Anderson has kept community physicians informed about advances in cancer care.