

Cancer Survival Gap: Progress Stalls for Young Adults

New Programs, Clinical Trials
Target Patients 15 to 40 in Effort
To Improve Recovery Rates

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In the past 30 years, new drugs and better treatments have helped many cancer patients survive longer. But one group hasn't benefited as much from these changes, leading some oncologists to focus increasingly on the role age plays in surviving cancer.

While children and older adults are surviving longer than they have in the past, rates for young people between the ages of 15 and 40 have barely budged. In the 25- to 35-year-old age group, a recent analysis of National Cancer Institute statistics showed that survival rates have not increased at all since 1975.

The perplexing stall in survival rates for this age group is generating a fresh round of research and treatment efforts. This year new clinical trials are opening, run by the Children's Oncology Group and others, that will explore issues surrounding cancer in young adults. In addition, major cancer centers, including the Dana-Farber Cancer Institute and M.D. Anderson Cancer Center, are creating programs to address a range of issues in treating young adults. And co-operative efforts involving private groups such as the Lance Armstrong Foundation are looking to identify new approaches and areas of research to fund.

Already, the latest research is providing valuable information for young cancer patients. Where a patient is treated can matter -- in studies of some cancers, young adults have done better at pediatric clinics, or on

pediatric treatment regimens, than with the adult protocols. A number of clinical trials are raising or lowering their age requirements to include young adults and adolescents, who have been little studied. And there is a growing realization that young adults have unique psychosocial issues that often aren't addressed at either pediatric or adult centers, and that doing so will improve the quality of their lives during treatment.

The possible reasons for the survival gap are wide-ranging. Some cancers may be biologically different in young adults, and less responsive to chemotherapy. Some aspect of the cancer treatment itself may be a factor, such as the kind or the dose of drugs or the way the drugs are given. Other obstacles young people face include a lack of insurance, and a later diagnosis because they don't always seek help for symptoms right away, and much lower participation in clinical trials that offer cutting-edge therapies.

Improving the survival rate for young adults would have an enormous impact. Cancer is the leading disease killer in people age 20 to 39. And while most people who get cancer are still over 65, more than 70,000 young adults between 19 and 40 get cancer every year, eight times as many as the number of patients under the age of 15. There is also an expectation that if scientists understand why this age group overall does worse, it could lead to the discovery of new genetic mutations, new mechanisms for the way cancer develops, or even new drugs that might apply as well to people in other age groups.

"By studying young adults, we hope to find key scientific insights into the disease that no one has ever looked at," says George D. Demetri, director of the Center for Sarcoma and Bone Oncology at Dana-Farber, who will help lead a trial later this year to study gastrointestinal stromal tumors in patients age 15-30.

Doug Ulman, director of survivorship at the Lance Armstrong Foundation and one of the driving forces behind the new focus on young adults, knows about some of the key issues from his own

experience. Diagnosed in 1996 at age 19 with chondrosarcoma, a rare cancer, then twice with malignant melanoma within the year, he said it was hard to find other people his own age to share his fears. He had just completed his freshman year at Brown University and was feeling more independent when suddenly he found himself relying heavily on his parents and family again. Back at school, instead of socializing or studying, he found himself obsessed with learning everything he could about cancer. "I didn't have the typical behavior of a 19-year-old," he says.

Mr. Ulman says that those age 15-40 with cancer often find themselves caught between two worlds -- feeling out of place in either a children's hospital with rooms decorated with Disney characters or in adult cancer centers surrounded in waiting rooms and support groups by people closer in age to their grandparents.

Essentially, young adults are a sandwich generation, with lower survival rates than children for cancers that primarily affect the very young, such as acute lymphoblastic leukemia and a soft-tissue cancer called rhabdomyosarcoma. And they do worse than those over 40 when they get cancers that are more common in older adults, like breast or colorectal cancer, according to the analysis of NCI data, by Archie Bleyer, an oncologist and medical adviser to the cancer-treatment center at St. Charles Medical Center in Bend, Ore.

New programs are being launched that aim to change that. Dana-Farber in Boston created a new adolescent and young adult oncology program that will do clinical research and provide cancer care and psychosocial programs for patients age 15-40. Memorial Sloan-Kettering Cancer Center in New York is developing a young-adult survivor program for those in their 20s, 30s and 40s when people are at high risk for "late effects" of cancer therapies that arise years after treatment, such as heart attacks. And in January, M.D. Anderson Cancer Center in Houston opened the Beth Sanders Moore Young Breast Cancer Survivors Program for women under 45 with breast cancer, who typically have more-aggressive types of cancer than older

women who get the disease.

The National Cancer Institute and the Lance Armstrong Foundation are also launching a progress review group that will study the issues of cancer in young adults. The yearlong project is expected to identify new directions in research, which the Lance Armstrong Foundation has committed to help fund. The foundation also helped establish the Live Strong Young Adult Alliance -- which includes groups like Planet Cancer, the Ulman Cancer Fund for Young Adults (which Mr. Ulman helped to found) and others -- in order to set a national agenda for young-adult cancer and help implement the recommendations of the progress review group.

In the past, young adults had particularly low rates of participation in clinical trials compared with other age groups, in part because fewer trials have been aimed at them. Efforts are now under way to make clinical trials more accessible. Trials run by the Children's Oncology Group, the major cooperative group of pediatric cancer institutions in North America, will now enroll patients up to age 40 in trials for osteosarcoma, Ewing's sarcoma, medulloblastoma and other cancers that have traditionally been studied almost exclusively in pediatric centers. And some cooperative groups of cancer centers that treat adults have lowered the age of eligibility for some of their trials in cancers that are more prevalent in older adults -- such as melanoma -- to age 10 from age 18, to allow adolescents to enroll.

At Dana-Farber, the upcoming GIST trial co-led by Dr. Demetri will explore how a particular cancer may be fundamentally different in different age groups. The disease in young adults "goes by the same name but is clearly a different disease," he says, noting that in older adults with GIST, around 95% have a certain kind of genetic mutation that responds well to a targeted therapy, Gleevec. But in those age 15-30, "a sizable proportion do not have that particular mutation," so Gleevec isn't as effective, Dr. Demetri says.

Still, this age group also more frequently gets a less-aggressive form of

the disease. If scientists can figure out why GIST in this age group behaves differently, it could lead to the development of drugs that could turn cancer in older people into "that same kind of kinder, gentler tumor," says Dr. Demetri.

One of the most disturbing findings of the emerging research into young adults is that where someone gets treated can make a dramatic difference in survival in some cancers. In a German study presented in 2003, young adults with Ewing's sarcoma did better when they were treated at pediatric centers than adult centers, even when they got the same drug regimen, leading some doctors to question whether psychosocial factors are also at work in addition to biology.

Richard Larson, a professor of medicine at the University of Chicago who is helping develop a trial for young adults with acute lymphoblastic leukemia (ALL), says young adults treated at pediatric centers may be more likely to benefit from what he calls the "mother factor," where patients are more compliant with their treatment regimens because their care is directed by their parents. He says some oncologists have also suggested that pediatric centers may be better at implementing chemotherapy regimens meant for primarily pediatric cancers, even when the same protocols are used in both children and young adults.

In three separate studies recently by groups in the U.S., Holland and France, significantly more 15- to 21-year-olds with ALL were alive five years after diagnosis when they were treated with a more-intensive pediatric drug regimen than when they got the adult protocol, said Karen Albritton, who heads the adolescent and young adult oncology program at Dana-Farber. She said that the adult protocol used less-intense doses of chemotherapy drugs because it was geared toward older adults, who often have a poor tolerance for high doses. But that meant many young adults were probably undertreated. A new trial being launched this year will examine survival rates of young adults age 15-30 with ALL, compared with other age groups who receive the same pediatric regimen, and with different age groups from previous studies.

"There are some young adults with cancer who should be getting different treatments than they are now," says Dr. Albritton. "Lives are being lost that shouldn't be."

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