

June 1, 2004 – The New York Times

New Approach About Cancer and Survival

By GINA KOLATA

Reprinted from The New York Times

Mike Gallo was 63 years old when he joined one of the world's fastest-growing fraternities.

He had reeled through the shock of learning that he had cancer, a B-cell lymphoma. He had endured the potent doses of chemotherapy, the exhaustion, the mouth sores. He lost every strand of his flowing wavy red hair.

And now he is emerging on the other side. He is happy the cancer was caught. He is happy that he is alive. But he finds himself tagged with a curious and confusing label: cancer survivor.

Before he became one, Dr. Gallo, the associate director for cancer prevention and control at the Cancer Institute of New Jersey in New Brunswick, thought he understood what it meant to be a cancer survivor. Now, he says, he realizes that he had no idea how it would change him, and how little was known about people like him. "I had intellectualized what cancer was about," he said.

So had many researchers. Until now, they have tended to focus on the initial cancer treatment. But now, defining a survivor as anyone who has received a diagnosis of cancer, the focus is much wider. There are now nearly 10 million cancer survivors in this country, up from 3 million in 1971 and 6 million in 1986.

Many live for years or decades, and it is becoming impossible to ignore their needs and unanswered questions about their lives.

Now, federal officials for the first time are hoping to figure out exactly who these cancer survivors are, how they should be treated, what their psychological states are, and what their medical and social needs are.

The survivors, and their doctors, need to know what to do when the initial treatment is over. How should they be screened, and how often, in looking for recurrences? What are the consequences of chemotherapy and radiation years or decades later?

And what about life as a survivor? Should you consider yourself cured or living with a chronic disease? What is the psychological impact of having had cancer, having what may be permanent disabilities from the disease or its treatment, and trying to go back to a life or a career that has been disrupted?

"What's new is the recognition and growing attention to the fact that people are living long term," said Dr. Julia H. Rowland, director of the Office of Cancer Survivorship at the National Cancer Institute.

Researchers are starting to ask what life is like after a cancer diagnosis. "What is the health cost, the societal implication?" Dr. Rowland said. "Is it different from someone with heart disease or diabetes? How much different is it to have cancer?"

In part, there are more survivors because treatment for some cancers is better. In part, it is because the population is older, and cancer is largely a disease of the elderly. And, in part, it is because there is more testing for cancer. While screening tests can find cancers at a stage when they are more amenable to treatment, it can also find cancers that would never have been noticed in the person's lifetime.

At the survivorship office of the cancer institute, grants for studies of cancer survivors have increased to 85 from 24 in 1999. The Centers for Disease Control and Prevention and the Lance Armstrong Foundation recently issued a report on cancer survivors, and two more national reports on the topic will be issued this week. Now, questions that were rarely asked in the past are receiving intense attention.

"This is a new field for us," said Kevin Brady, acting director of the division of cancer prevention and control at the centers for disease control. But, he said, the need for answers is pressing.

"We heard from constituents, from survivors," Mr. Brady said. "They were saying, 'There's a lot we don't understand. Now that we know people are living longer, what are the other impacts as we survive, as we age?'"

They are, of course, impossible to categorize, the nearly 10 million Americans who have had cancer diagnoses. Some have tumors — in the lung or pancreas, for example — that defy treatment. Others, like men with prostate cancer, usually have no symptoms of cancer and no recurrences after they are treated but the treatments themselves, radiation or surgery, can render them impotent or incontinent.

But these cancer survivors do have one thing in common. The prospect of death is no longer a cerebral awareness but is an unavoidable part of daily life.

"One knows in the abstract from a very early age that life is limited and that there is an end to it," said Musa Mayer, a New York writer, breast cancer survivor and advocate for breast cancer patients. "But the first time your own death has a name attached to it, the first time you can clearly see the path from here to there, is a life-changing experience."

Few are prepared. Even medical experts who thought they knew all about cancer say the raw emotions, the icy fear of hearing that they themselves have cancer can push all their intellectualizing aside.

For Dr. Gallo, the loss of innocence came on a cold Friday afternoon in February when he and his wife were driving on the Connecticut Turnpike, on their way to Cape Cod to work on their vacation home. His cell phone rang, a call from the surgeon who had removed a small lump from Dr. Gallo's groin. Dr. Gallo and the surgeon had been sure it was inconsequential.

"There's no good way to say this," the surgeon said, before bluntly telling Dr. Gallo that he had B-cell lymphoma. And suddenly, Dr. Gallo realized that all his medical knowledge of cancer had not prepared him for the reality. He was terrified.

"I was convinced I would die," Dr. Gallo said.

Cancer survivors also share the realization that they can never return to life as it was before the cancer diagnosis.

Some changes are tangible: the old job may not be there anymore, insurance may be denied. Others are more subtle: a change in the way friends, family, colleagues view you.

Sometimes old relationships resume.

"People who were old friends, old acquaintances heard through the grapevine that I had cancer," Dr. Gallo said. "Everyone said: 'We were so close in the past. I'm so sorry we drifted apart.'"

Sometimes relationships wither.

"Either people start avoiding you," Ms. Mayer said, "even crossing the street to avoid seeing you, or you get these meaningful looks. How ARE you?"

"You become aware of people's preconceptions and biases," she went on. "All of a sudden, the world divides itself into two kinds of people. Those who get it and those who don't. Those who have been in contact with their own fragility and those who have not."

Cancer also becomes part of the person's identity, whether they seek it or not, said Dr. Jimmie Holland, a psychiatrist at Memorial Sloan-Kettering Cancer Center in Manhattan.

"One man," he recalled, "said to me, 'I used to be just Joe. Now I'm Joe, the cancer patient. Why can't I go back to being just Joe again?'"

"You can't," Dr. Holland said.

For Doug Ulman, director of survivorship studies at the Lance Armstrong Foundation, being a survivor means understanding that the initial treatments are just the start of a new life. At age 26, Mr. Ulman has had chondrosarcoma, a rare tumor that produces cartilage, and two episodes of melanoma.

"I never dreamed I would have cancer," Mr. Ulman said. "But what I realized is that there was very little support out there for people who were really thinking longer term about their lives. Not, 'Will I live or die?' But, 'How well will I live?'"

The questions are daunting, researchers and patients say. Some are being addressed by new reports on cancer survivors. A Report to the Nation, from the National Cancer Institute, the North American Association of Central Cancer Registries, the Centers

for Disease Control and Prevention, and the American Cancer Society, will be issued at the end of this week. It analyzes trends in survival, comparing survival 25 years ago to today and discussing why the improvements may have occurred.

The President's Cancer Panel's report, also to be released at the end of the week, focuses on survivors' medical needs, psychological needs and on issues like health insurance and how survivors' needs depend on their age at diagnosis.

Another report, earlier this month, by the centers for disease control together with the Lance Armstrong Foundation called for, among other things, registries to follow cancer survivors to learn the long-term consequences of treatments and for programs to help patients live with medical conditions resulting from their disease and its treatment.

One thing that is needed, medical experts say, is better information on how to follow patients after their initial treatment. Should they have screening tests? Which tests? How often? Those questions are mostly unanswered except for breast cancer patients, where studies found that annual mammograms and physical examinations are adequate, Dr. Rowland said. Although women may be periodically tested with blood tests for tumor proteins, chest X-rays and bone scans, "women who do the full nine yards don't do any better," Dr. Rowland said. "It turns out that less is more."

Another need is for follow-up care, Dr. Rowland said.

"Follow-up care is not offered routinely and so if you need rehabilitation," she said, "or if you become depressed after treatment or have chronic fatigue or chronic pain or cognitive problems, you wouldn't necessarily have access to resources. We don't really have guidelines for what that follow-up care should look like."

But another way of looking at the issue, said Dr. Maurie Markman, vice president for clinical research at the M.D. Anderson Cancer Center in Houston, is to take note of the reason the discussions are even taking place.

"I grew up in an era where our goal was to cure the cancer," Dr. Markman said. "It was this mind-set: Give high doses of chemotherapy. Hit them harder." There were just two outcomes, he said. "You were cured of cancer or you died."

But, he said, the mind-set has changed. He sees it in his own specialty, ovarian cancer, where many women now live five years, ten years or even longer after the initial diagnosis.

"We talk of control, of preventing tumor growth," he said. "Conceptually, it's an incredible paradigm shift. We will not necessarily be able to eliminate this invader but we will be able, with drugs, to let you live with it for some undefined period of time. And not in bed so sick that you wonder if life is worth living."

For now, Ms. Mayer said, the fundamental issue for cancer survivors is uncertainty. Is the disease gone or will it come back? What did those treatments do to you?

"It's, 'Do I have or did I have?'," she said. "It's an existential choice and the truth is that I don't know. But people often make a choice: 'I will see myself as cancer-free.' Or, 'It's chronic. It could come back at any time. I am living with cancer.'"

"It's the not knowing that is really the critical issue," she said. "It's living with uncertainty, learning to live with that."