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From Scan to Scan: The Challenges of Living with Metastatic Cancer

A growing population of people living with advanced or metastatic cancer has raised questions about the unique needs of these individuals.

October 25, 2021 By National Cancer Institute

Since 2018, Bethany Ross has started a new job, run four half marathons, and been treated for metastatic cancer.

The 33-year-old software engineer was diagnosed with stage IV neuroendocrine cancer 3 years ago, after vomiting every day for months. Doctors at the Dana-Farber Cancer Institute found tumors in her appendix and pancreas and cancer cells that had spread to her liver and nearby lymph nodes.

After two surgeries and hormone injections to treat her symptoms, Ross received good news: Doctors could no longer detect cancer in her body. She currently is not receiving any treatment for cancer, but every few months for the rest of her life, Ross will go to Dana-Farber for tests, including imaging scans, to see if the cancer has started to grow again.

“My doctors say the disease will come back at some point—they just can’t tell me when,” said Ross, who lives in New Hampshire. “With each scan, I wonder if this is the one that will reveal a recurrence.”

But Ross is not just waiting for the cancer to come back. She works full time and runs. She has also spoken at medical conferences, including a recent NCI-sponsored workshop, about her experience living with metastatic cancer.

Ross is part of a growing population of individuals who are living longer with advanced or metastatic cancer than was once possible.

“New treatments, such as targeted therapies and immunotherapies, have led to a real transition in survivorship,” said Jennifer Temel, M.D., of Massachusetts General Hospital, who studies cancer survivors and spoke at the NCI conference.

“People can stay on these treatments for many years, which means they can survive for many years,” Dr. Temel added.

Until recently, long-term survivors of advanced or metastatic cancer have primarily been women with metastatic breast cancer. But doctors are now seeing survivors with other types of cancer, including lung, gastrointestinal, kidney cancer, and melanoma.

The emergence of a growing population of people living with advanced or metastatic cancer has raised questions about the unique needs of these individuals and how to improve their care.

Igniting a New Field of Research

To address these questions, NCI sponsored a virtual meeting that brought together researchers, health care providers, patient advocates, and people like Ross who are living with advanced or metastatic cancer.

The meeting featured presentations by survivorship researchers and people living with advanced or metastatic disease, as well as panel discussions. Each panel included at least one person living with cancer.

“We came together to exchange ideas about how we are caring for these patients and what we can do better,” said Temel. “Our goal is to ignite a new field of research to better support and address the care needs of patients with advanced cancers.”

People living with advanced or metastatic cancer have needs that may differ from those of people who have been treated for early-stage cancers, noted Lisa Gallicchio, Ph.D., of NCI’s Division of Cancer Control and Population Sciences (DCCPS), who co-led the meeting.

Examples of these needs include the management of chronic conditions, psychosocial support, caregiver support, financial support, and communication around the goals of care.

“People with advanced or metastatic cancer might require treatment for the disease indefinitely, or they might be on and off treatment for the rest of their lives,” Dr. Gallicchio said. “They will also likely undergo regular testing to identify signs of a recurrence.”

The Psychological Impact of Uncertainty

Although newer therapies can help some patients live longer, clinicians cannot predict how long a treatment is going to be effective for an individual patient. “The psychological impact of this uncertainty on patients and their loved ones was a theme of the [NCI] meeting,” said Dr. Temel.

Jamil Rivers, who was diagnosed with metastatic breast cancer 3 years ago at age 39, spoke at the conference about the uncertainty of living with the disease. “When you learn that you have metastatic cancer and see the survival statistics, it can be overwhelming emotionally,” said Rivers. “And if you’re living with metastatic cancer, you’re living from treatment to treatment, from scan to scan.”

Rivers said that her latest imaging scans had not shown any tumors. “But I still have metastatic cancer,” she explained. “I have to be on some type of treatment to keep that cancer at bay so that it doesn’t grow and wreak havoc on my body.”

Rivers also described financial challenges related to cancer. She did not tell her employer about her diagnosis so that she could maintain her salary and her family’s health insurance, which was through the employer. She continued to work for the year that she received chemotherapy.

“Life doesn’t stop when you get diagnosed with cancer,” Rivers said in an interview after the meeting. “I have a family to take care of. We have a house, and I need to put food on the table and buy the kids clothes.”

Rivers has founded the Chrysalis Initiative, a nonprofit organization that aims to improve the lives of women of color with breast cancer, who have historically had poorer outcomes than other women with the disease. She has also shared her story through the national media, putting a spotlight on the needs of people living with metastatic cancer and their loved ones.

At the conference, Rivers issued a call to action: “For all future studies and initiatives around cancer survivorship, we should ask: How does this research also help meet the needs of patients with metastatic cancer?”

Helping Patients with “Scanxiety”

The stress that often accompanies the routine imaging scans that patients undergo to monitor changes in their health is sometimes called “scanxiety.”

“Scanxiety is a real phenomenon,” said Dr. Temel. “It’s natural to feel anxious when you’re waiting for an important test result, and I don’t think there’s a quick fix to it.”

Providing patients with information they can understand about their diagnosis and treatment is one way that Dr. Temel tries to support her patients and lessen their stress. “We know that when patients have accurate information, they are better prepared and make more appropriate decisions about the future,” she said.

She also conveys a message to her patients and families: “We’re going to be here for you whether the scan result is good news or bad news, and we have a plan for the future.”

This reassurance may make the period of anxiety and worry slightly less distressing, Dr. Temel said. Then she added, “I hate waiting for test results, too. It’s part of being human.”

Including Many Perspectives

Emily Tonorezos, M.D., director of NCI’s Office of Cancer Survivorship, said the conference created opportunities for researchers, clinicians, advocates, and people living with advanced cancer to exchange ideas. A publication summarizing the main discussions is in the works.

“The importance of including the perspectives of patients and survivors in designing, conducting, and interpreting research findings emerged as a theme of the meeting,” said Michelle Mollica, Ph.D., of the Healthcare Delivery Research Program in DCCPS, who co-led the meeting.

Christine Hodgdon, a patient advocate who is living with metastatic breast cancer and moderated a session at the meeting, said the presence of people living with advanced cancer on every panel conveyed an important message:

Researchers need to hear from people who are living with advanced cancer. “This was the first meeting I’m aware of that focused specifically on survivorship and advanced cancer,” added Hodgdon, who lives in Maryland and co-founded the organization Guiding Researchers and Advocates for Scientific Partnerships (GRASP), which brings researchers and patients together as equal partners.

“We believe there is a need to involve people with advanced disease in research and not just as participants in clinical trials,” said Hodgdon. Patients could help plan a trial, she suggested, or assist even earlier in the process, when researchers are asking, “What should I study?”

Following Long-Term Survivors over Time

Investigators at the meeting stressed the need for large longitudinal studies that follow people living with advanced or metastatic cancer over time, collecting information on the cancer types, treatments, and health histories of long-term survivors. Very few such studies exist, but they could help identify the unmet needs of patients and strategies for addressing these needs.

Data from longitudinal studies could also reveal clues about why some patients with metastatic cancer survive for extended periods and potentially how to help more patients live longer, several researchers said. But they cautioned that the research will be challenging.

Long-term survivors are “an incredibly heterogeneous” group, Dr. Gallicchio noted. “These individuals are from diverse backgrounds and have different cancer diagnoses,” she continued. “They have also been treated with different therapies or treatment regimens.”

Exactly how many people are living with advanced or metastatic cancer is not known, but a 2017 study found that the number of women living with metastatic breast cancer had been increasing.

Supporting Caregivers and Coordinating Care

At the conference, many participants stressed the need to learn more about how best to support the caregivers and family members of long-term survivors.

Rivers, who has three children, shared some challenges. “Parents who are living with metastatic cancer may need help ensuring that their kids are supported emotionally,” she said after the meeting. “Cancer treatments have a lot of side effects, and it can be both scary and challenging to have conversations about these side effects with your family.”

Another challenge is coordinating care among various health care providers. People living with advanced or metastatic cancer often receive new treatments, and oncologists may need to communicate with primary care physicians about which side effects and possible complications to expect and how to address them.

Health care providers also have limited information about the long-term side effects of newer treatments, which is another reason that the coordination of care and communication among providers is important, several researchers noted during the NCI meeting.

As new treatments for cancer are developed and cancer care improves, the importance of understanding the needs of people living with metastatic or advanced cancer will increase.

“The science is advancing so rapidly,” said Bethany Ross. “With these new and highly effective therapies, more groups of patients are going to be living for longer periods of time.”

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