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HEALTH

Debate Heats Up On Defining A Cancer Survivor

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Who should be considered a cancer survivor? Now that more people are living many years after diagnosis, the debate over how to define a survivor is heating up.

It used to be that someone who had completed treatment and was still alive five years after diagnosis was considered a survivor. But this definition has changed in recent years. In the national action plan for cancer survivorship being released next month by the Centers for Disease Control and Prevention and the Lance Armstrong Foundation, survivors are defined as anybody who has ever been diagnosed with cancer -- no matter if the diagnosis was yesterday or 20 years ago.

The Office of Cancer Survivorship, which is part of the federal National Cancer Institute, defines a survivor as someone who finished his or her cancer treatment at least six months earlier -- when it comes to spending research dollars.

Lisa R. Diller, an oncologist at the Dana-Farber Cancer Institute in Boston, says that a cancer survivor used to be someone who is no longer undergoing treatment such as radiation, chemotherapy or surgery. "But this may not be a valid definition any longer either," Dr. Diller added.

New treatments such as Gleevec or tamoxifen are frequently given to patients chronically or for years, even in instances where they may technically be considered cancer-free by their doctors.

Further fogging up the definition: Family members, friends and caregivers of someone living with cancer are now commonly being called survivors.

The change in the way the community defines itself may ultimately change the way cancer, and those living with it, is studied. Many research projects have been done retrospectively, where survivors are

interviewed years later about their experiences during the early days of the disease.

"We think people should be studied and followed from the time they are diagnosed," says Doug Ulman, who survived bone cancer and melanoma and is now director of survivorship at the Lance Armstrong Foundation.

"Otherwise it is difficult to validate data about what happened to someone five years ago."

It may also lead to better ways to identify people most at risk for side effects and future health problems, and better prevention interventions.

For the cancer community, finding the right term has been tricky, and remains an ongoing debate. Some people don't like the word survivor because it is so closely associated with the Holocaust or victims of violent crime such as rape. They point out that people who have heart attacks are not called "heart attack survivors."

Rochelle Shoretz, 31 years old, was diagnosed with breast cancer in 2001 and has been told by her oncologist that she is now considered "disease-free."

But because she still takes the drug tamoxifen in order to lower her risk of recurrence, "I find it difficult to embrace the term survivor. There is still medication in my body. Can you really consider yourself a survivor when breast cancer is still so much a part of your life?"

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