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Survivorship in Focus

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*In 1986, when Patricia Ganz, MD, helped found the [National Coalition for Cancer Survivorship](#) (NCCS), treatment and research were central to any scientific conversation about cancer, but “post-treatment” was only beginning to gain traction as a concern. The young oncologist nevertheless had begun clearing a path as a pioneer for a specialty emphasizing healing after cancer treatment ends. Today, with more and more cancer patients living well beyond treatment, survivorship is becoming embedded in the medical landscape. Ganz, a University of California, Los Angeles professor of health services and medicine as well as author of *Cancer Survivorship: Today and Tomorrow* (Springer), a book aimed at cancer professionals, also is recipient of last year’s American Cancer Society’s Distinguished Service Award. She is invigorated by the growing focus on survivorship and spoke recently to freelance writer Jean Nash Johnson about how surviving cancer has progressed in recent decades.*

How has the concept of “survivorship,” in terms of patient care once primary cancer treatment has ended, evolved over the past 20 years?

What happened was, with the founding of the NCCS, we defined a *survivor* as a person with cancer from the time of diagnosis until death and including the family, which was broad and all-encompassing. If you just looked at the post-treatment phase, you would not focus on treatment decisions that would be made earlier that could affect the post-treatment survivorship phase. In 1986, fewer people were living disease-free for a long period of time, but a growing number were experiencing uncertainty about their future, as well as some of the serious side effects of treatment.

But the [Institute of Medicine] committee study and report in 2005, “From Cancer Patient to Cancer Survivor: Lost in Transition,” focused on the fact that we now have this large body of people, probably now about 12 million, who are living post-treatment, many disease-free, many 20 years past diagnosis and treatment. We need to acknowledge that the post-treatment period is a special segment of the survivorship trajectory.

How has this evolving concept been integrated into practices and institutions that affect patient care—as well as payment for care?

We’re on the very early part of an adoption curve. Cancer centers are usually the lead places where innovations occur. In order to change practice behavior, it usually takes the additional resources and personnel that a cancer center often has. It takes changing behavior within the cancer center environment because that’s where you’re training new doctors.

One of the cardinal recommendations of the IOM was that every patient should have a treatment summary at the end of cancer treatment that tells patients what kinds of treatment they had, what kinds of things to look out for. Well, until we start training our medical oncology fellows and surgery fellows in the cancer centers that this is what you do, they are not going to be translating that into their community practices.

What should cancer patients expect from each member of their oncology team (oncologist, oncology nurse, social worker) to help prepare them for survivorship?

Again, the oncologist needs to be the person who summarizes in written form the treatment the patient had, any known short- or long-term side effects and how patients need to be followed after—how long they need to be seen, blood tests, X-rays, exams they will need and at what intervals, and who needs to be responsible for what.

The oncology nurse may help in making this plan but also may deliver the information and counsel the patient about diet and exercise, stress management, follow-up care, relating to how the patient can promote better health and prevent a cancer recurrence. The oncology nurse can also meet with the patient through post-treatment

Social workers are very important [because] many patients are particularly concerned about psychological and social issues. Maybe they were off work during treatment and now have to go back. There could be changes in family relationships, depression, anxiety.

What are the key quality-of-life issues that linger for patients long after cancer treatment has ended?

Pain, fatigue, anxiety and depression, body image changes [loss of body parts, scars, weight gain or weight loss], sexuality. Right now we don't have a very good system of post-treatment care. The goal is that someone sits down and does a treatment summary and survivorship care plan and at least identifies concerns the patient may be having, even if the doctor or the nurse doesn't have the skills to address some of these things. Let's say you ask, "How is your sex life?" [and] do a little probing to see what might be going on? The patient may deny a concern but will know that the provider is concerned and may bring it up in the future. The patient can be referred to a sex therapist.

Typically what happens is that the patient comes back into the office and it's: "Oh, well the cancer hasn't come back. You're doing great." That [attitude] is what we want to try and get beyond.

Given that more than half of all cancers are diagnosed in people older than 65, what specific attention should be paid to the needs of older cancer survivors?

Sometimes cancer treatments make pre-existing problems that older people have worse. For instance, some of the drugs or other treatments can enter the heart muscle and cause heart failure or other organ damage—kidney, lungs. There may be some clinical changes in organ functions, or pre-existing abnormalities can be made worse.

It's very important that we communicate closely with the primary care physician

so these areas are not neglected.

Social support and concrete needs such as transportation to see the social worker, for example, may be very important to the older patient because often older people are caregivers to an older spouse. It's important to make sure that they are getting follow-up cancer surveillance.

What remains to be done to better serve cancer survivors throughout their lives?

The fundamental thing is that we need more research done on what some of the late effects are. For breast cancer, perhaps, we have a lot more information. We don't have good descriptive epidemiology and risk factor data and you'd like to have that data so that you could prepare patients so that you can say, "Oh it's an extremely rare event."

For breast cancer, leukemia can occur from chemotherapy. It's extremely rare, less than 1 percent. I have that data and I can tell that to the patient. But if somebody had radiation and chemotherapy for lung cancer or colon cancer, we don't have long-term follow-up for the treatment regimens we have. We don't have good information on whether taking a treatment causes a specific problem in the future, [linked] to specific drug recipes, if you will. More [research] money needs to be invested.

Again the challenge with cancer is that it probably represents a hundred different kinds of diseases with different disease treatments.