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MH Issues in Cancer Survivors Persist Long After Treatment Ends

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People with cancer benefit from empathic care that helps them deal with the uncertainties with which they may always struggle.
By 2026 there will be more than 20 million cancer survivors, an increase of more than 4 million in 10 years, according to the National Cancer Institute. It goes without saying that, for the most part, these growing numbers of cancer survivors are, first and foremost, thankful to be alive. But long after treatment has ended and the patients' exams report NED (no evidence of disease), a cancer survivor is never really "cancer free."

"When a cancer patient completes treatment, everyone expects him to return to life as it was before cancer," says Alan Hsu, M.D., an assistant clinical professor of psychiatry at Moores Cancer Center at the UC San Diego Health. "But he is not the same person." Whether the patient was receiving psychiatric care before cancer, psychosocial post-cancer issues arise—including anxiety, depression, fear of recurrence, cognitive impairment, body image issues, and fear of intimacy—that often call for professional help.

Hsu frequently sees survivors after they no longer need to see their oncologist. “They’re often more anxious and depressed than they were while undergoing treatment,” Hsu told *Psychiatric News*. “They think that they should feel better, but they don’t, and it’s important for them to know that that’s perfectly normal.”

One Survivor’s Story

As both a cancer survivor and a journalist, writing the article on cancer survivorship holds a special significance for me.

When I was diagnosed with breast cancer 10 years ago, my fear was not that I was going to die—my own mother had gone through breast cancer twice (before ultimately dying of unrelated lung cancer). My fear was how my life was going to change. Despite the fact that I write frequently on health care, I’m a tad, shall we say, on the health-phobic side. I knew enough about cancer (in fact, at the time I was the editor of a breast cancer newsletter) to know that the rest of my life would be filled with many more doctors’ visits than I’d like and that with every symptom that arose, I’d be gripped by panic.

Once I got through the initial diagnosis and treatment planning, I settled down to some extent. I was assured by all the doctors that the cancer was early stage. I planned out the calendar and figured I’d be done by Christmas and back to my life. Just a bump in the road of life, I told myself.

Unfortunately, that all flew out the window, and I learned firsthand about cancer being a “roller coaster ride,” as social worker Jill Kaplan said.

Diagnosis, testing, even surgery all went fine. But after one chemo session, my colon ruptured. Severe, life-threatening complications landed me in the hospital for two months, followed by additional surgeries including a temporary colostomy, radiation therapy, and yet more surgeries including, a year and a half later, a colostomy reversal.

Once I was more or less back on my feet—almost two years later—a psychiatrist I knew asked me what I had learned from the experience. I blithely responded that I wasn’t sure anything significantly had changed, other than that I had managed to survive. As the years have gone by, however, I see now how naïve I was. While every day I’m reminded that I’m a cancer survivor, as I take my daily pill (only for six more months!), every day I am also thankful for my health. But along with the gratitude have come difficult emotions and experiences. With every routine mammogram and MRI, I suffer from “scanxiety.” I’m pretty much resigned to the fact that this will never go away, and I just get through it as best I can.

I saw both a psychiatrist and an oncology social worker, both of whom were an enormous help to me, but what I now know is that the ramifications of cancer extend far behind the initial diagnosis and treatment. They may be ongoing, they may change over time, and they may come when you least expect them.

From my standpoint as a cancer survivor, however, I'd like to echo those I interviewed for this article: Prescribe medication when needed. But go deeper, even if someone is only there for a prescription. See that person for who she was before cancer and for who she is now. Help her accept that she may not be the same. And help her realize that's OK.

According to the Centers for Disease Control and Prevention, 10 percent of cancer survivors report that they have poor mental health, compared with only 6 percent of adults who have not had cancer. Mental health problems among cancer survivors can lead them to forego healthy lifestyle choices such as improved diet and physical activity. Less than one-third of survivors who experience mental health issues discuss them with their doctor, and many do not take advantage of professional counseling or support groups.

"Healing starts after treatment," says Jill Kaplan, M.S.W., L.C.S.W., program director of the Cancer Support Community of Central New Jersey, who works closely with members of the psychiatric community. "That's when emotional side effects creep up."

One common side effect Kaplan sees among survivors is a feeling of isolation. "Often priorities have changed for the survivor, but not necessarily for their family and friends, who are expecting the same person to emerge from this life-changing experience," said Kaplan. "The adjustment can be challenging." In contrast, Kaplan continued, some survivors struggle with the notion that they haven't changed enough from their experience.

For those who didn't have a healthy lifestyle before having cancer, there may be a sense of guilt, as well as a newfound dedication to caring for oneself. For those who did everything "right," there is often a sense of betrayal. "I hear survivors say, 'I took care of myself, and I still got cancer.' They don't know what to trust anymore."

Working with those who have experienced cancer often calls for a collaborative approach across the various mental health disciplines, said Kaplan, but she observes that survivorship is not a linear process. "Where we meet a survivor isn't necessarily where you might meet them."

No matter where along the survivorship continuum a patient is, Kaplan suggests anyone working with a cancer survivor ask specific questions, such as: What was your life like before cancer? What is it like since cancer? How have you changed—physically, emotionally, spiritually, even financially? "We need to understand the whole person and how cancer has altered his life," said Kaplan, adding that she gives cancer patients, survivors, and all those working with them the same advice: "Roll your sleeves up, and strap yourself in. It's going to be a roller coaster ride."

"Every cancer survivor is going to experience some cancer-related distress," agreed Allison Applebaum, Ph.D., director of the Caregivers Clinic at Memorial Sloan Kettering, which has developed a survivorship program that includes psychosocial services. For survivors whose post-cancer distress is not disabling, a cognitive and behavioral approach is often sufficient to help them adapt to their "new normal." For survivors who may be experiencing post-cancer trauma—even if it doesn't meet the DSM requirements for PTSD—psychiatrist-prescribed medication along with counseling may be in order.

The end of treatment, while a cause for celebration, is often a trigger for anxiety and depression, according to psychiatrist Lorenzo Norris, M.D., assistant dean of student affairs at George Washington University School of Medicine and Health Sciences and former director of GWU's Survivorship Center Psychiatric Services. "They reach a transition point when active treatment is completed, and they feel that they're on their own," he said. "That can be a huge hurdle, especially for those who may not have a robust social network."

Norris said it's important for psychiatrists and other mental health professionals to provide survivors an opportunity to talk about their experience and understand how it fits into their own life narrative.

"You don't have to be a psycho-oncologist," says Norris, "but you should be comfortable working with those in the field of oncology and with those who are experiencing the stresses that survivorship brings, including family members who are also significantly affected by the illness."

Norris remarked that for himself, his work with cancer patients and survivors is among his most authentic and rewarding experiences.

For Allen Dyer, M.D., Ph.D., a professor of psychiatry and behavioral sciences at George Washington Univeristy and current director of its National Cancer Survivorship Resource Center, his professional role is also very personal. Dyer himself is a cancer survivor and knows firsthand that "it's not over when it's over."

"Experiencing cancer is like living through a tsunami," he says. "It comes over you unexpectedly, and, if you survive, you must live with a new reality."

The feelings that accompany that new reality change over time, according to Dyer, but they can arise at any time, even years later. "You may have been so busy just trying to stay alive that you didn't ever have a chance to talk about your feelings," he said.

Dyer's own survivorship has included the common "stages of grief," though with some modifications. Instead of denial, for example, it was more "disbelief," he recalled. And rather than acceptance, it was more like "coming to terms."

"As a cancer survivor, you have to come up with your own expressions of your unique experience," he said.

Even now, 19 years after a bone marrow transplant to treat his multiple myeloma, Dyer said that he and his wife sometimes look at each other and think, "How did we get through that?" To answer that question for himself and for others, Dyer wrote a book, One More Mountain to Climb, that talks about his personal relationship with illness, health, trauma, and resilience.

While additional training in psycho-oncology is useful when working with cancer patients and survivors, it is not necessary, Dyer tells other psychiatrists. "The skills you already have are translatable. Just be empathic and help your patients tell their story." ■