

Psychological challenges of surviving cancer

Transitions are particularly tough; some problems emerge at unexpected times.

About 11 million Americans alive today—one in 30 people—are either currently undergoing treatment for cancer or have done so in the past. The National Cancer Institute considers all to be cancer survivors. Many would attest that cancer is not only life-threatening, but also life-altering.

Cancer and its treatment sometimes leave scars and other physical changes that can have long-lasting effects. Even so, many cancer survivors remain psychologically healthy. Some are happy simply to be alive. Others have developed greater self-esteem, confidence, and resilience, as well as a stronger appreciation for day-to-day life after having faced a formidable disease.

But some cancer survivors struggle with “subthreshold” symptoms of depression, anxiety, and post-traumatic stress disorder. Although these problems may not meet the criteria for a clinical diagnosis, they are often significant enough to cause suffering and disrupt lives, sometimes for years.

Adjusting to life after treatment

The psychological terrain of survivorship is dynamic, with the most difficult times occurring during transitions. Dr. William Pirl, a Massachusetts General Hospital (MGH) psychiatrist who works frequently with cancer survivors, believes that one transition in particular is likely to cause psychological distress: the period immediately following completion of intensive (primary) cancer treatment. For some patients, this transition may be as stressful, if not more so, as undergoing treatment itself.

This is counterintuitive. Patients, family, and friends understandably look forward to the completion of cancer treatment, especially when the prognosis is good. But when patients complete what may have been a gruel-

ing series of daily, weekly, or monthly medical visits, they also lose both the support system and structure provided by regular contact with an oncology team and other patients.

Furthermore, friends, co-workers, and even family members may not fully appreciate what cancer patients have gone through emotionally and physically, and so expect patients to return to “normal.” But cancer survivors typically feel more vulnerable, anxious, and uncertain about the future after treatment ends.

How these challenges affect individual cancer survivors depends on a variety of factors, including age, overall psychological functioning, coping skills, social supports, and the type and severity of cancer.

Ongoing concerns

Cancer survivors contend with a number of ongoing psychosocial issues.

Fear of recurrence. Understandably, given cancer’s potential to spread (metastasize), as many as nine in 10 patients are afraid that their cancer will recur. Although this fear tends to subside with time, certain events—such as follow-up medical visits, unexplained pain, or particular sights and smells associated with treatment—can trigger bouts of anxiety and fear that are as debilitating as those that occurred during treatment. Dr. Pirl finds that cancer survivors may become increasingly irritable and experience sleep difficulties as long as a month before a follow-up medical visit, although they may not be aware of what is causing their distress.

For some survivors, anxiety about a cancer recurrence is not episodic, but far more pervasive and disruptive. These patients may become hypervigilant about their health, with every unexplained symptom causing anxiety. Others may go to the other extreme,

even to the extent of avoiding necessary medical care.

Fatigue. One of the most common legacies of cancer treatment is a persistent lack of energy or overall weariness. Getting extra sleep does not help in most cases, and cancer-related fatigue remains poorly understood.

A general guideline is that for every month of cancer treatment, it will take a month to recover previous energy levels. But in some cases, it may take longer. One study that followed 763 breast cancer survivors found that about 34% reported significant levels of fatigue five to 10 years after diagnosis.

Dr. Pirl, who runs the MGH Cancer-Related Fatigue Clinic, says that survivors often underestimate the time it takes to recover and may become discouraged if they can’t resume their previous lifestyle as soon as they’d hoped. Or they become anxious, fearing that the fatigue may signal a cancer recurrence.

“Damocles syndrome.” Some cancer survivors, having confronted a life-threatening illness, may become so fearful about what may befall them in the future that they can no longer enjoy life as they once did. Some may have a hard time making major life decisions, such as whether to get married

For more information

American Cancer Society
Cancer Survivors Network
<http://csn.cancer.org>

American Psychosocial Oncology Society
www.apos-society.org

National Cancer Institute:
Cancer Survivorship Research
<http://cancercontrol.cancer.gov/ocs>

National Coalition for Cancer Survivorship
www.canceradvocacy.org

Survivors of childhood cancer

About 270,000 Americans are survivors of cancer diagnosed during childhood. In 1993, the National Cancer Institute launched the Childhood Cancer Survivor Study, a long-term, retrospective study of 14,000 survivors and 3,700 siblings, to better understand the physical and psychological challenges encountered by these survivors.

Confirming earlier research, the study reported that most childhood cancer survivors who reached adulthood were psychologically healthy and just as emotionally well adjusted as siblings. But a separate report painted a less rosy picture of childhood cancer survivors still in adolescence, who were 1.5 times more likely than siblings to have symptoms of depression or anxiety, and 1.7 times more likely to act out at school and display other types of antisocial behavior.

Problems with cognitive abilities are also common in both adolescent and adult survivors of leukemia, lymphoma, or

brain tumors—which account for about 60% of childhood cancers. Children with these cancers typically receive radiation or chemotherapy treatments that penetrate the brain, causing long-term problems with physical growth and with learning, short-term memory, and attention.

So far, interventions using drugs or psychotherapies to improve cognitive function in survivors of childhood cancer have produced limited success. For example, a randomized controlled trial involving 161 pediatric cancer survivors concluded that a cognitive remediation program that combined cognitive behavioral strategies with special education and brain injury rehabilitation techniques only modestly improved attention and academic achievement. The research continues, but for now the advice is to work with schools to develop accommodations and special education interventions to help the child learn as much as possible.

or change jobs. This emotionally paralyzing fear, first noticed in survivors of childhood cancer, is often referred to as the “Damocles syndrome.” According to the Greek legend, Damocles was unable to enjoy the banquet spread out before him once he realized that a sword dangled precariously overhead.

Stress responses. Long-term effects of dealing with the stress of cancer diagnosis and treatment include difficulty sleeping and concentrating, physical symptoms such as heart palpitations, and fearfulness or hypervigilance. Studies have estimated that up to one-third of cancer survivors may suffer symptoms of post-traumatic stress disorder, depending on the methods used and populations studied, although only a minority meet diagnostic criteria for the disorder.

Cognitive changes. Problems with attention, concentration, and memory—sometimes referred to as “chemo brain”—may persist for months after chemotherapy ends. It’s not clear what causes these problems, although certain patients seem to be more vulnerable than others, possibly for genetic reasons. One study found, for example, that post-treatment cognitive problems were more likely in patients who have a particular version of the apolipoprotein

gene known as APOE4 (which also increases risk of Alzheimer’s disease). It’s also possible that some drugs are more toxic to brain cells than others, or that a combination of several agents may contribute to problems.

Survivor guilt. Cancer survivors who lose members of a patient support group, or patients they got to know during treatment, experience loss and grief—sometimes repeatedly, as time goes on. Although they may be happy to be alive, cancer survivors may also feel guilty that they survived and their friends did not.

Exercising body and mind may help

Two reviews that examined only randomized controlled trials (most involving breast cancer patients) concluded that aerobic exercise or strength training improved overall quality of life, helped alleviate fatigue, and enhanced physical functioning. Questions remain about which regimens work best and how to tailor exercise routines to specific phases of survivorship.

One study involving 483 breast cancer survivors who had stopped treatment five to nine years earlier randomized the women to usual care or to an intervention that combined cognitive behavioral and self-help strategies.

At a follow-up assessment 20 months later, the women who had participated in the intervention showed more improvement in coping ability.

Many clinicians had hoped that psychosocial interventions would help survivors live longer. Although recent literature has been disappointing on that score, the studies have been small and experts disagree on how to interpret them. Thankfully, there is ample evidence that such interventions do improve quality of life in various ways.

Clearly more research needs to be done. But if physical activity, cognitive behavioral therapy, and other types of interventions help ease distress and make life more enjoyable, then that may be reason enough for cancer survivors to consider them. ♥

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For more references, please see www.health.harvard.edu/mentalextra.