

OCCASIONAL NOTES

Seasons of Survival: Reflections of a Physician with Cancer

WHEN I was given a diagnosis of cancer, my first thought was not, Will I die? but rather, How can I beat this? Like a youngster who flunks a big test, I immediately began to worry about what to do to pass the course. I was 32 years old at the time, a physician, a husband, a parent, and a son. I had been healthy, athletic, and free of pain, but with the diagnosis, I became formally sick. My mind and my hopes riveted

immediately on the goal of cure. *Cure*. The word itself became magic for me, a time when everything would be all right again, when the shadow in my life would be gone, when normal life would resume.

The tumor manifested itself as a mediastinal mass that I discovered on a chest x-ray film. During a subsequent closed mediastinal biopsy my innominate vein was inadvertently punctured, requiring an emergency thoracotomy and some heroic surgery to save my life. The tumor proved to be an anaplastic primary seminoma, and I underwent treatment with radiation and chemotherapy in the following months. After a toxic course, the tumor appeared to be arrested, and I regained strength and returned to work. A year later, intractable osteoradionecrosis of the sternum developed, necessitating a sternectomy followed by a multiple-stage plastic surgical repair of the chest. After that I recovered again and returned to work, a bit the worse for wear but, as it turned out, free of tumor.¹

It did not occur to me while I was acutely ill or for some time afterward that the simple concepts of sickness and cure were insufficient to describe what was happening to me. As with most cancer patients, the quality of my life during this period was severely compromised, and the possibility of death was always present. I was, in fact, surviving, struggling physically and mentally with the cancer, the therapy, and the large-scale disruption of my life. Survival, however, was not one condition but many. It was desperate days of nausea and depression. It was elation at the birth of a daughter in the midst of the treatment. It was the anxiety of waiting for my monthly chest film to be taken and lying awake nights feeling for lymph nodes. It was the joy of eating Chinese food for the first time after battling radiation burns of the esophagus for four months. These reflections and many others are a jumble of memories of a purgatory that was touched by sickness in all its aspects but was neither death nor cure. It was survival — an absolutely predictable but ill-defined condition that all cancer patients pass through as they struggle with their illness.

During these years I frequently wondered when I could safely declare victory. When could I say simply that I was cured? Actuarial and population-based figures give us survival estimates for various cancers, but those figures do not speak to the individual patient, whose experience is unique and not determined or described by aggregate data. Many patients are "cured" long before they pass the five-year mark, and others go well beyond the five-year point with overt or covert disease that removes them from the ranks of the "cured," no matter how well they feel. Survival is a much more useful concept, because it is a generic idea that applies to everyone diagnosed as having cancer, regardless of the course of the illness. Survival, in fact, begins at the point of diagnosis, because that is the time when patients are forced to confront their own mortality and begin to make adjustments that will be

part of their immediate and, to some extent, long-term future.

Living on, as I have been fortunate to do, I have reflected on my experience and talked to many cancer patients about their experiences. Although the binary notion of cure versus noncure is understandably appealing to everyone concerned with cancer, most agree that it is not an accurate characterization of the experience. The vagaries, phases, and syndromes of survival are far more complex than that simple idea suggests. Moreover, the binary concept implies that there are two separate courses: one for those who are cured and one for those who are not. On the contrary, the events, therapies, and emotions that all patients go through are, to a point, similar. Patients with cancer, whether recently diagnosed and being treated or previously diagnosed and relatively stable, have more in common with one another than they do with people who have not experienced cancer. Although the circumstances and outcomes obviously vary enormously from person to person, I think that most patients go through some relatively predictable and potentially useful stages of survival. I do not suggest that these are formal stages in a strict clinical sense, but rather that there is a progression of events for most cancer patients that is definable in its general outline — the seasons of survival.

ACUTE SURVIVAL

The first season begins with the diagnosis of the illness. It is really the medical stage and is dominated by diagnostic and therapeutic efforts to stem the tide of illness. Fear and anxiety are important and constant elements of this phase, since all but the very young and the infirm have the ability to appreciate the gravity and life-altering potential of their diagnosis. People universally and reasonably fear cancer, and as a consequence, the mere fact of the diagnosis creates a state of mental ill-being that is sometimes more punishing than the biologic presence of the disease. Pain is also a common element of this stage, since both the illness and its treatment can cause considerable discomfort.

This is a time, too, when patients are called on to deal with their own mortality. Most of us assume that we are going to live for a long time into the future. The diagnosis of cancer immediately aborts that comfortable notion. We are forced to deal with the fact that we may be dead soon, that we may not see our grandchild born, or our daughter go to college, or next Christmas. Confronting one's own mortality is an immutable characteristic of the acute stage.

This season is defined and dominated by cancer treatment — medical, surgical, and radiologic. Simply coping with the effects of the therapies occupies all the adaptive energies of most patients. Family and community support of the sick person is an important buffer to the harsh realities being experienced. An often overlooked aspect of this phase is the needs of the patient's family. Backing for these "secondary pa-

tients" can take many forms but is often neglected in the rush of sympathy for the new patient.

EXTENDED SURVIVAL

When the patient goes into remission or has terminated the basic, rigorous course of treatment and enters a phase of watchful waiting, with periodic examinations and "consolidation" or intermittent therapy, the acute phase is over, and the season of extended survival has begun. Psychologically, this time is dominated by fear of recurrence — the punishing worry that the tumor, now in abeyance, will return to resume its perfidious work.

This is usually a period of physical limitations, since the tumor and treatment have exacted a corporal price. Diminished strength, fatigue, a reduced capacity for exercise, amputation of a body part, or hair loss occurred in the acute phase, but now they must be dealt with in the home, the community, and the work place. An altered body image and, perhaps, a different vocational role are intertwined with physical limitations to make reentry at home and at work a trying experience that calls for strength, patience, and a sense of humor.²

Unlike the acute phase, the elements of which are somewhat more uniform and predictable, the experiences of individuals in the extended period are as variable as their diseases, their adaptability, and their home and work situations. Responses range from isolation, devastation, and depression to minor disruption or anxiety.

Since this phase is not predominantly a medical one, doctors and nurses tend to have a diminishing role in providing support and counseling. The result is a void that leaves many cancer patients and their families fending awkwardly for themselves in the "healthy" world. A small but growing number of local groups and publications in various parts of the country address the needs of persons passing through this difficult phase. (The "I Can Cope Program" of the American Cancer Society is the most widely available program of this sort.) People who succeed in connecting with support services such as these tend to do it by word of mouth or through referrals from other patients. Treatment plans for patients in this postacute phase rarely address the psychosocial problems of reentering the active world. Systematic referrals by oncologists, primary care physicians, and nurses to support services for patients at this point in their recovery would do a tremendous amount to aid adjustment, relieve suffering, and stimulate the further development of these scarce resources.

PERMANENT SURVIVAL

The term "permanent survival" will not be found in the literature. It can be roughly equated with the phenomenon we usually call "cure." Permanent survival, however, has several dimensions beyond those of victory over the disease, including specifically a kinship and continuum with the previous seasons of survival.

There is no moment of cure but rather an evolution from the phase of extended survival into a period when the activity of the disease or the likelihood of its return is sufficiently small that the cancer can now be considered permanently arrested.

The patient in this phase is indeed a survivor. Whatever our wishes, the person who has come through a cancer experience is indelibly affected by it. The Humpty Dumpty idea of "as good as new" — a powerfully appealing notion for cancer patients — simply does not pertain. For better *and* for worse, physically and emotionally, the experience leaves an impression. No matter how long we live, cancer patients are survivors — at once wary and relieved, bashful and proud.

Problems with employment and insurance are common for persons who have been treated for cancer and are ready to resume a full life. Many people experience discrimination of various sorts as they seek employment and advancement.^{3,4} Health and life insurance are predictably troublesome issues, with many companies evincing reluctance to insure cancer patients or excluding coverage for anything remotely related to the disease. Not only do some people encounter prejudice as they seek work, but others who are able to resume their former jobs become "locked in," unable to advance or change their employment because of the vocational and insurance fallout from their former illness.

The long-term, secondary effects of cancer treatment on health represent another area in which permanent survivors are at risk. Secondary tumors have been reported in successfully treated cancer patients as a result of various oncolytic agents.⁵⁻⁸ The long-term noxious effects of radiation also appear to be an area of concern.⁹⁻¹¹ As such information is reported in the literature, it is important that permanent survivors and their physicians be kept informed. Primary care physicians, who provide most of the care for this group of cancer patients, are irregularly and unpredictably informed of these developments, and the patients themselves have no way to learn about them.

Reproductive health for young people who have been successfully treated is another rapidly changing area in which up-to-date information is not always available to general physicians or patients. The concerns here include the frustrations of sterility, the risks of mutagenicity, and guidance on matters of adoption. Advances in the treatment of acute lymphocytic leukemias in children, as well as Hodgkin's disease and germ-cell tumors, have greatly increased the number of young survivors.¹² For them the issues of health maintenance and particularly reproductive health are enormously important.

A STRATEGY FOR SURVIVORSHIP

The Herculean effort that the United States has put into cancer research and treatment over the past two decades has resulted in a substantial increase in survival. As recently as 1960, only 25 per cent of patients survived five years or more, whereas today the figure is

approaching 50 per cent.¹³ Despite this success on the treatment front, we have done very little in a concerted and well-planned fashion to investigate and address the problems of survivors. It is as if we have invented sophisticated techniques to save people from drowning, but once they have been pulled from the water, we leave them on the dock to cough and splutter on their own in the belief that we have done all that we can. The current status of cancer treatment is a prime example of what Lewis Thomas calls "half-way technology" — technology that is far more effective than it used to be but that is gross and ineffective compared with what it will become.¹⁴ As we move from an earlier time when few cancers were treated successfully to the point when virtually all of them will be cured, we are passing through an uncharted middle ground, which in many aspects remains primitive. The challenge in overcoming cancer is not only to find therapies that will prevent or arrest the disease quickly but also to map the middle ground of survivorship and minimize its medical and social hazards.

In this spirit, a thoughtful, coordinated national research enterprise in the area of cancer survival needs to be undertaken. Survivorship should be studied as a phenomenon in itself rather than as a byproduct or afterthought of basic research on cancer treatment. Organizations such as the National Cancer Institute and the American Cancer Society need to collaborate with interested groups and individuals in developing such a program. As a concept, survivorship has biomedical and psychosocial components. On the biomedical side, secondary tumors, the long-term effects of treatment, rehabilitation, reproductive health, and long-term health maintenance warrant systematic investigation. On the psychosocial side, such issues as community acceptance of cancer patients, insurance discrimination, barriers to employment, and education of youth about cancer need to be explored.

Cancer survivors themselves need to improve their communications. Currently, there is no ready source of information for people concerned with the issues of survival. An information network, even for such items as existing support groups or the status of laws concerning discrimination, does not exist. There is no publication written for a lay audience that provides periodic updates on the many long-term concerns of cancer patients. What is needed is a consumer network — really an alumni association — of cancer survivors, with meetings, newsletters, and periodicals. Individuals and groups concerned with cancer should focus on the development of such a network.

An appreciation of the seasons of survival will help both patients and health professionals develop better strategies for dealing with the difficult life event that cancer represents. The use of a staging system for the survival period will assist clinicians and those responsible for research policy to address the specific needs of patients and former patients at various points of their experience. Moreover, a sense of the progres-

sion of stages will help patients and their families cope with cancer and shepherd their energies in as useful a fashion as possible. This strategy promises to produce important improvements not only in the quantity of survivors but in the quality of survivorship in the future.

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