
CHAPTER 2

From Anecdote to Evidence: The Survivor's Perspective

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Tell me a fact and I'll listen.
Tell me a truth and I'll learn.
But tell me a story,
And it will live in my heart forever.

—Native American Wisdom

INTRODUCTION

Storytelling is the foundation for the concept of survivorship. Without the stories of individuals struggling to survive the difficult treatments, persistent side effects, unexpected life disruptions, and bewildering unknowns of long-term survival, there would be no knowledge of the true impact of this disease. Only through anecdotal reporting or storytelling do we ever progress to systematic observation and evidence-based care. Thus, stories become an important and integral component of current everyday practice, transitional care, and long-term follow-up.

I feel compelled to admit to personal bias in this chapter, as my own experiences with cancer have greatly influenced my professional life as an oncology nurse and advocate. I always struggle with the decision to include my cancer history within my writing because anecdotal accounts usually are considered “unprofessional” in an academic sense. Yet, it is from these experiences that I have been able to make contributions to my chosen profession of oncology nursing. Also, stories from untold numbers of survivors over the past decades have surely influenced the other authors who are contributing to this book. Consequently, I have added an occasional encapsulated snippet from my own encounters with cancer to illustrate this theme of survivorship.

ONCE UPON A TIME

Sometimes I feel like a primitive artifact that survived the early era of cancer care, as my personal experiences have paralleled that of oncology as a medical and nursing specialty. When I received treatment for Hodgkin disease (now called Hodgkin lymphoma) in 1972, there were no effective antiemetics, no colony-stimulating factors, and no central vascular access devices. There were also no support groups, extremely limited patient resources, and very few nurses specializing in cancer care. Technicians were employed to deliver radiation therapy treatments and monitor side effects, and in the beginning, only physicians could administer chemotherapy. Because cancer treatment initially was available only in limited academic settings, chemotherapy drugs were sometimes sent home with instructions for local physicians to deliver an occasional dose. I still remember receiving nitrogen mustard in my antecubital vein from an older physician who had never before given chemotherapy. He chided me for my vanity in wanting to save my hair as I sat there with a tourniquet around my hairline! Needless to say, many antecubital veins were irreparably damaged, and countless hair follicles failed to survive various tourniquets and ice packs. Fortunately for patients everywhere, nurses soon became interested in cancer care as a separate specialty and, in 1975, started the Oncology Nursing Society. The safe delivery of these new therapies, along with offering supportive care and symptom management, became their priorities.

Finally, a new sense of hope emerged. From a provider perspective, the hope that some types of cancer might become treatable, controllable, and maybe even curable offered tenuous yet exciting possibilities. From a patient perspective, hope became entangled with an undefined yet encouraging sense of “future” that cohabitated with undercurrents of anxiety and fear. Meanwhile, success was still measured numerically in months and years of life, and survivors were often told how lucky they were to be alive and how grateful they should be. No complaining allowed. End of story.

DOWN THE WINDING ROAD

As survival advanced from months into years, cancer-related issues changed for both survivors and caregivers. Throughout the 1980s, physical survival was no longer considered the only measure of success. As increasing numbers of patients lived longer after receiving different forms of cancer therapy, attention turned to the quality of the lives being saved. Symptom management quickly became the responsibility of oncology nursing, yet crisis management for psychosocial problems was hit-and-miss depending on staff availability. With limited support services, oftentimes no one was present to hear the stories of insurance and employment discrimination; of lingering or delayed psychological trauma; of destroyed relationships,

infertility, or sexual difficulties. This collateral damage simply represented the price patients paid for survival.

More collateral damage occurred as care became increasingly fragmented. As much of the physical care moved from acute inpatient settings to ambulatory outpatient environments, psychosocial care remained extremely limited, undervalued, underfunded, and rarely a priority. While oncology nurses and social workers became increasingly frustrated with the lack of psychosocial resources for those in active treatment, the increasing number of long-term survivors was far down the list of priorities for continued attention. Consequently, survivors and caregivers took it upon themselves to create opportunities for continued support.

The complexities of surviving a life-threatening disease were generally identified *not* by systematic follow-up within oncology clinics but rather through individual and collective *stories* shared by survivors whenever and wherever they could find each other. While many survivors simply wanted to forget the entire experience, others were desperate to find fellow survivors with similar issues and fears. They gathered in church basements and at each others' homes. They started support groups, hotlines, and organizations, all so that they could share their stories and prevent others from suffering in silence. One of the first newsletters dedicated solely to patients and survivors was created by Pat Fobair, a social worker at Stanford University, and was called *Surviving*. I remember reading every single word and saving every single issue. It felt like a lifeline for so many survivors and helped to create a sense of connection while validating the complexities of survival. The entire content of this publication was composed of *stories!* Patient stories. Survivor stories. Caregiver stories. Wounded lives now had an outlet for healing.

TRANSFORMING WOUNDS

Often we forget that the medical narrative of someone's disease and treatment describes but one piece of a complex life story. In *The Wounded Storyteller: Body, Illness, and Ethics*, Arthur Frank (1995) wrote that people who have been affected by illness "need to become storytellers in order to recover the voices that illness and its treatment often take away" (p. xii). For years I didn't even realize that I had a voice. In *Building a Legacy: Voices of Oncology Nurses* (Leigh, 1995), I wrote, "Over the years as I had mentioned some of my concerns to physicians and nurses, I often found myself patronized, ignored, or labeled a hypochondriac" (p. 290). Why was I still afraid? Would I ever feel safe again? How do my colleagues deal with their emotions and the intensity of this work (oncology nursing)? The nurses and physicians I worked with simply did not understand my lingering anxieties. What more did I want? After all, I was one of the lucky ones because I was in remission. So I shut down and said nothing, as did many survivors who had lost their voices. But that all changed in 1986.

SURVIVORS UNITE

From the mid-80s and into the next decade, we saw the beginning of a consumer movement. The Wellness Community, Candlelighters, Cancervive, Commonweal, Vital Options, Cancer Lifeline, and (People) Living Through Cancer are just a few examples of the very early programs that started independently around the country to support patients and families who were dealing with cancer. As these consumer groups were creating diverse models of community-based care, psychosocial support programs were also beginning to emerge in hospitals and clinics. Surely one of the most recognized and respected programs was I Can Cope, started by Judi Johnson and Pat Norby (Johnson & Klein, 1994)—visionary nurses who blended academic pursuits and clinical experience into an educational support program that was subsequently adopted by the American Cancer Society.

Along with these programs and community resources came multiple consumer-oriented books. Titles such as *Hanging in There: Living Well on Borrowed Time* (Spingarn, 1982), *From Victim to Victor* (Benjamin, 1987), *The Road Back to Health: Coping With the Emotional Side of Cancer* (Fiore, 1984), and *Cancervive: The Challenge of Life After Cancer* (Nessim & Ellis, 1991) represent an early sampling of works written about and by survivors or caregivers. At the same time that survivors were sharing their experiences through writing, oncology physicians, nurses, and social workers joined in and helped organize these many sources of support. To help coordinate this movement, a diverse group of advocates came together in 1986 and founded the National Coalition for Cancer Survivorship (NCCS, n.d.). The founding members began to change the language about survival to reflect the lived experience of this new population. The term *survivor* replaced *victim*, and the concept of *survivorship* illustrated the multiple dimensions and stages of survival. Fitzhugh Mullan (1996), the cofounder of NCCS, wrote eloquently about survivorship and described it as

the act of living on, no matter what happens, the challenge faced daily by millions of Americans who are engaged in defiance of disease and in affirmation of life, and lifelong, beginning with the diagnosis of cancer and continuing for the balance of life. (p. xvii)

In the beginning, survivorship was qualitative and had no boundaries. It described the dynamic process of survival rather than containment in time frames (five years) or outcomes (cure). In metaphorical terms, it was initially seen more as a journey than a destination.

THE NEVER-ENDING STORY

Although significant progress has been made in the field of survivorship, challenges continue. As the number of survivors increases, so does the need to expand the continuum of care to include adequate, affordable, and accessible long-term follow-up care. Yet, even if money becomes available to cover

long-term costs, the question still remains about who will care for the long-term cancer survivors and how. The good news is that earlier diagnoses and better treatments are improving survival. The not-so-good news is that the longer we live, the greater risk we have to develop other cancers and delayed effects of treatment.

Furthermore, at the same time the needs of survivors are increasing, the numbers of both oncologists and primary care providers are decreasing. So, who will care for survivors? If resources are limited, choices must be made. Obviously, patients in need of life-saving treatments for active disease are top priority for oncologists. But how long will they be able to continue caring for an increasing population of survivors who are at risk for possible problems? As more and more survivors experience second malignancies and late effects of treatment, there is growing anxiety about who is available, willing, and qualified to oversee their follow-up care.

I like to think that oncology nurse practitioners (ONPs) will be the answer to these dilemmas. ONPs have been at the forefront of survivorship care in pediatric oncology for years. Although they are now playing a larger role in adult follow-up care, there simply are not enough of them. But it is still a place to start. Most ONPs have “knowledge gained through delivering and monitoring treatments and managing side effects. They also develop relationships with family members and loved ones, assess for psychosocial problems, refer to appropriate specialists, and generally work within a model of wellness promotion rather than disease management” (Leigh, 2007, p. 11). ONPs have the opportunity to position themselves as preeminent providers of survivorship care.

IMPROVING SURVIVORSHIP CARE

Oncology nurses in general play an ever-expanding role in preparing their patients for life beyond cancer. Although clinic nurses may no longer see long-term survivors for anything but a quick hello during an annual checkup, they play a critical role in helping patients transition to post-treatment care. Here are some of my own personal recommendations from a survivor perspective for improving transitional and long-term care (see Figure 2-1).

- **Celebrate, but with a dose of reality.** Help prepare survivors for the transition to post-treatment care. Obviously, it is exciting to see your patients

Figure 2-1. Recommendations to Improve Transitional and Long-Term Care of Cancer Survivors

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| <ul style="list-style-type: none"> • Celebrate, but with a dose of reality. • Complete a treatment summary. • Prepare survivors to leave their safety net. | <ul style="list-style-type: none"> • Encourage survivorship care plans. • Honor survivors' "labels." • Look outside the (evidence-based) box. • Value survivors' stories. |
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complete treatment and graduate to follow-up care. But be aware that this can be a frightening time for survivors. After you celebrate the end of treatments with graduation certificates, songs, cupcakes, or bubbles, many survivors leave the clinic, sit in their cars, have panic attacks, and wonder, “What do I do now? How will I know if the cancer is coming back? Why am I feeling afraid when I should be feeling happy that treatments are over?” Remember to offer the tools of resources, referrals, and reassurance to help them survive the unknowns.

- **Complete a treatment summary.** Hopefully, most survivors will soon have one of these important documents. This is a simple historical report listing the specifics of the patient’s diagnosis and treatments. It includes any problems that occurred during treatment, along with any lingering effects. Can anything be done to alleviate or treat these problems, and who is responsible for follow-up? Who can be contacted if a problem or question arises? Make sure that all survivors have a copy of their individual treatment summary and care plan and that copies are sent to their primary care provider and other specialists.
- **Prepare us to leave our safety net.** Oncology physicians and nurses have been our safety net for months and even years. It can be frightening to think about returning to primary care providers who may not know how to care for us or how to identify possible treatment-related problems. How long can survivors continue to come to the oncology clinic for checkups? Will an oncology nurse be available to take calls and answer questions that can arise months or years after treatment is completed? Who will help update survivorship care plans?
- **Encourage survivorship care plans.** The Institute of Medicine released its report *From Cancer Patient to Cancer Survivor: Lost in Transition* in early 2006. It then published *Implementing Cancer Survivorship Care Planning: Workshop Summary* in 2007; this was such an important component of the original work. It highlighted the role of nurses in coordinating cancer survivorship care planning. While the treatment summary is a static report, the survivorship care plan is an ever-changing, living document. Because it changes, it requires time and regular attention. Gathering the team to first develop, and then update, this plan can be daunting. But this is where survivors learn to be *well* again. Even though surveillance is a critical part of post-treatment care, it is always frightening to think about what might be found during follow-up visits. A more palatable component of follow-up care is health maintenance and health promotion. If survivors are informed that future clinic visits will focus on learning how to be well, many will feel much more enthusiastic about coming in for follow-up appointments. Teach survivors about diet and nutrition, exercise, and stress reduction. Ask about relationships, sexual problems, or any other issue that needs attention. Make referrals when necessary, and personalize plans with tools and resources that will help survivors regain a sense of control and reduce their fears.

- **Honor our “labels.”** Some of us love to be called *survivors*. Others hate the label. Whether we prefer to call ourselves *thrivers*, *victors*, *warriors*, *activists*, *cancer killers*, or simply *cancer patients*, honor how we view ourselves. I like to think that arguing about how we want to be labeled or what we want to be called is a real sign of progress! But you may occasionally need to remind us that we are much more than our cancer diagnosis and that a cancer label is only one part of who we are.
- **Look outside the (evidence-based) box.** Although few evidence-based guidelines are available to direct survivorship care, we can no longer use this lack of evidence to ignore appropriate follow-up. Initially, common sense determines the testing and timelines for follow-up care. The next step is to agree on consensus-based guidelines while waiting for the research-based evidence.
- **Value our stories.** Storytelling is how we find meaning through suffering. It makes our experiences unique and gives dimension and texture to our lives. Continue to listen to us, as it is through each of our stories that you will learn how to care for us. Survivors continue to be guides to the unknowns.

FROM SURVIVING TO THRIVING

Oncology care surely has come a long way over the past four decades. But there is still a long way to go. As scientific research continues to unlock the mysteries surrounding cancer, more effective treatments are emerging to extend and improve the lives of those affected by this disease. Meanwhile, the voices of the survivors themselves must never be lost in discussions and decisions surrounding survivorship care. This passage from the Institute of Medicine report (2006) *From Cancer Patient to Cancer Survivor: Lost in Transition* serves as a reminder and guide:

By also reviewing reports that summarize the anecdotal and compelling stories of survivorship, we heard the voices of survivors who underwent a life-changing experience—learning that large numbers of them are dealing with a legacy of physical, psychological, social, vocational, spiritual, and economic consequences. Hearing about their experiences further opened our eyes to the unspoken and hidden disabilities that follow successful treatment for cancer. (p. xxiv)

It is my hope that this increased awareness about the consequences of survival will expand access to comprehensive follow-up services, increase research in the area of lingering and late effects, encourage more systematic follow-up and inclusion in databases, and enhance our focus on “wellness” and improved quality of life. Oncology nurses need to make sure that survivors have access to insurance coverage for rehabilitation, along with referrals to specialists, mental health services, and end-of-life care, and need to afford all survivors the opportunity to not only survive but to thrive after cancer.

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