

# CONQUERING THE CANCER CARE CONTINUUM™

## The Importance of Survivorship Care Plans

Lillie D. Shockney, RN, BS, MAS

In this issue of *Conquering the Cancer Care Continuum* you will learn about a hot topic that most cancer centers and oncologists are struggling to make a reality: survivorship care plans for all cancer survivors at the end of (acute) treatment, coupled with a comprehensive treatment summary. There is good news and bad news to share with you about the need for this document. The good news is that there are more people than ever being diagnosed and surviving their cancer and its treatment. This is due to a swell in the population's denominator caused by aging baby boomers, the largest age group in the United States today. Second, early detection, more awareness of symptoms, better technology, and compliance with cancer screening have resulted in more people being able to survive their disease. The bad news is that there is a growing shortage of oncology specialists due to reimbursement issues and other factors. This shortage will grow to a deficit of between 41% and 48% by the year 2020. It will therefore be virtually impossible for an oncologist to follow a cancer survivor long-term in the clinic. Those patients, also nicknamed the worried well, will need to get off the exam table to allow newly diagnosed cancer patients to come in and begin treatment.

When I think about it, I reflect back to the 1970s when we held disaster drills in the ER that impacted the inpatient nursing units. The faux disaster meant

that we needed to find a certain number of inpatient beds for patients who were injured in some way, so as nurse manager I would quickly make rounds on my unit to identify patients who would be good candidates for potentially going home a day or so sooner than originally planned. And after the drill was over, it wasn't unusual to speak with the treating doctor and ask if the patient really could go home today, drill or no drill. Though the days are long gone of having patients linger in a hospital bed for any length of time beyond what is truly needed from a medical necessity perspective, we now need to turn our attention to the outpatient clinic arena. If a physician normally sees 5 newly diagnosed patients and 20 long-term follow-up patients in the Wednesday medical oncology clinic but is now being told to see 9 newly diagnosed, what will he/she do?

Well, no one can put 10 pounds of salt into a 5-pound bag. This capacity issue will require the discontinuation of following cancer survivors long-term. And doesn't it kind of make sense anyway? What message are we sending to our patients who are several years to decades out from completing their treatment? That we think their cancer will come back?

We cannot simply tell patients that we are "done" taking care of them and instruct them to return to their primary care physician (PCP), who was not afforded the opportunity in medical school to learn

*(continued on page 4)*



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# The Importance of Cancer Survivorship Care Plans: A Nurse's Perspective

Beth Fairman, PhD(c), MSN, APRN-BC, AOCN

## Question:

Which of these patients would benefit from a cancer survivorship care plan (SCP)?

1. Evan is a 28-year-old male who was diagnosed with testicular cancer 6 years ago. He underwent surgery and chemotherapy and has no evidence of disease. He plans to get married next year but wonders what the chemo “has done to my body,” and if he will ever be able to have children “normally.”

2. Patricia is a 72-year-old female diagnosed with breast cancer 3 years ago. She is currently undergoing radiation to a new metastatic lesion in her left hip. She is recently widowed.

3. Mary is a 52-year-old female diagnosed with B-cell, non-Hodgkin lymphoma last year. She achieved a complete response and is seen every 3 months. She just lost her job as a waitress.

4. Andy is a 68-year-old male diagnosed with multiple myeloma in 2003. He has been on multiple chemotherapy regimens and achieved a partial remission to treatment. He remains on continuous oral chemotherapy and lives alone.

5. All of the above.

## Answer:

All of the above.

## The Importance of Cancer Survivorship Programs

Cancer remains the second leading cause of death in the United States, and the American Cancer Society estimates there are approximately 13.7 million cancer survivors in the United States, with 18 million projected by 2022.<sup>1,2</sup> According to the National Cancer Institute, cancer survivorship covers the physical, psychosocial, and economic issues of cancer from diagnosis to the end of life, which encompass the true “costs” of cancer.<sup>3</sup> Interest into the underlying concepts of survivorship has increased tremendously in the past decade as patients are living longer than ever. In the growing population of cancer survivors, many are burdened by a host of challenges as a consequence of

survival. Thus, cancer survivorship is a major public health concern, as a multitude of factors can negatively impact the patient’s family, friends, and community.<sup>4-6</sup>

Although several definitions exist, a cancer survivor is defined as an individual with a cancer diagnosis who must deal with the sequelae of the cancer itself and the effects of the treatment.<sup>7</sup> Side effects of cancer and its therapy can be short-term or long-term and are not always in the physical domain. Short-term effects may include a temporary disability or change in living situation. Long-term effects can be physical, such as chronic graft-versus-host disease, development of heart disease secondary to cardiotoxic chemotherapy, or inability to pay the mortgage. Issues that cancer survivors deal with are mostly unique to cancer, but similarities are seen in patients with end-stage

renal disease who are on dialysis, or in organ transplant recipients. Nurses and providers must be aware of these issues and open discussion when appropriate and ensure follow-up surveillance for long-term complications.

Physical health status and the prevention of long-term complications are important components of cancer survivorship. Cancer patients are at a higher risk of developing preventable illnesses and experience a poorer health status than noncancer patients. A large cohort study of 2522 cancer and noncancer patients evaluated the incidence of noncancer health-related problems, self-reported health condition, and ability to carry out activities of daily living. Individuals with cancer were more likely to develop cardiovascular disease, endocrine disease, or diabetes than noncancer patients, and they were also more likely than other age- and gender-matched individuals to report poor health status.<sup>8</sup> This study illustrates that patients with cancer are vulnerable to health conditions that can negatively impact quality of life and emphasizes the importance of preventive health maintenance (HM) screening.

Preventive HM is an important aspect of care in all patients, and it is especially critical to cancer survivorship. HM encompasses procedures that aim to prevent illness, maintain maximum function, and improve the health of the individual. Recommendations for HM



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screening are made by the World Health Organization and agencies such as the US Preventive Services Task Force (USPSTF), a branch of the Department of Health and Human Services. The USPSTF has issued guidelines for primary and secondary preventive services in all persons based on age, sex, and risk factors for disease. Although patients with cancer are at the same or increased risk for illness due to concurrent medications used to treat or manage their cancer, cancer patients fail to participate in routine HM screening.<sup>9</sup> Encouraging weight loss, a healthy diet, and smoking cessation are HM practices that cancer patients can benefit from.

Barriers to adequate HM and follow-up care after the initial cancer treatment exist. A major reason for insufficient HM in cancer patients is based on erroneous patient and provider beliefs. Surveillance and screening for primary and secondary health conditions in patients with an existing cancer diagnosis has been viewed by some providers and patients as unnecessary because the life expectancy is already shortened by the cancer. Lack of provider knowledge of appropriate screening and the unique needs of cancer survivors remains an issue despite evidence of improved cancer survival. Further, patients themselves are unclear as to what treatments they received for their cancer or their specialized needs following cancer treatment.<sup>10</sup>

Psychological, social, and financial issues are prevalent in cancer patients. Fear of cancer recurrence, loss of employment, loss of medical insurance, and physical impairment are commonly cited fears of cancer survivors. A multidisciplinary team of specialists that includes psychiatry, social work, and rehabilitation specialists is necessary to appropriately address the unique needs of the cancer survivor and the family. Regardless of the cancer stage at diagnosis, all cancer patients can benefit from a well-designed cancer survivorship program.<sup>7,10,11</sup>

## A Call for Action

Major organizations have recognized the need to improve the quality and consistency of care provided to cancer survivors. In 2004, *A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies* was developed by the Centers for Disease Control and Prevention (CDC) in alliance with the Lance Armstrong Foundation. The Institute of Medicine (IOM) recognized the specialized needs of cancer survivors in a 2005 report.<sup>12</sup> The goal of these papers was to identify the needs of cancer survivors, ensure all survivors have appropriate care and resources, and implement methodology for improved health-related outcomes.<sup>5,10</sup>

Survivorship programs have grown tremendously in

recent years since the CDC and IOM reports. Major organizations such as the American Society of Clinical Oncology, the National Comprehensive Cancer Network, the Commission on Cancer, and the Oncology Nursing Society are just a few of the groups that have placed an emphasis on developing programs to meet the patients' needs. Major hospital systems have cancer survivorship programs either in existence or in development. These structured care models address the aforementioned components of survivorship and SCP development.

SCPs are individualized plans of care that can be presented to cancer patients during or after completion of treatment. Many variations of the SCP exist and are tailored toward each patient group, such as the care plan created by the International Myeloma Foundation Nurse Leadership Board for patients with multiple myeloma.<sup>12</sup> A tool for SCP building can be found at <http://journeyforward.org/professionals/survivorship-care-plan-builder>. This resource allows providers to develop an SCP for cancer patients, their primary care physician, and other members of the treatment team.

Each of the patients listed in scenarios at the beginning of this article would benefit from an SCP created by the nurse or healthcare provider. Whether the patient is a young male who received chemotherapy for testicular cancer or an older female with lymphoma, the SCP addresses the specific needs of each patient. A team-based approach to care with primary providers, oncology physicians, nurses, pharmacists, social workers, physical therapists, and nutritionists provides resources essential to the well-being of the patient.

Nurses and healthcare providers are in a position to promote the importance of HM and survivorship programs to cancer survivors by educating themselves and others. Patient education about the improved survival, the chronicity of cancer, and the risk of secondary conditions should begin as soon as relevant in the treatment continuum. Providers should remind the patient that monitoring of the cancer itself and other illnesses must be ongoing. As patients with cancer are living longer than ever, nurses and healthcare providers will continue to play a key role in the early diagnosis and prevention of noncancer-related illness in patients with cancer, in explaining the benefits of survivorship programs, and in facilitating referrals.

## Conclusion

Cancer is a chronic disease in the United States. Most cancers are incurable but treatable. In this growing cancer population, improved survival comes with physical, financial, and emotional costs. Survivorship

programs continue to grow to address the unique needs of cancer patients. Nurses and healthcare providers can effectively create a personalized SCP for each patient that focuses on the importance of HM and continued follow-up cancer care. Screening for health conditions or cancer secondary to treatment is critical, as research suggests that patients with cancer have the same or increased risk of developing illness as other patients without cancer. Knowledge of modifiable risk factors such as smoking cessation and a healthy diet can lead to decreased noncancer-related morbidity. Healthcare providers play an important role in providing education about the importance of HM and in partnering with PCPs. ■

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## The Importance of Survivorship Care Plans *(continued from page 1)*

about cancer survivorship care. And the patients have bonded with us, and us with them for that matter. They are our warm fuzzies in a clinic filled with stressful decision making, anxieties running high among our newly diagnosed patients and their families, and the need to repeat over and over the treatment options. Who wants to give up the warm fuzzies for long and more stressful consultations with newly diagnosed patients? But we must. There is no other option.

Preparation for such a transition is best established at the very first consultation when patients are newly diagnosed with cancer. Informing patients of how the phases of treatment will be carried out and at what point they will transition back to their PCP is important because it establishes expectations. A road map for their ongoing care, however, is also needed. The PCP needs to know what his/her responsibilities are relative to cancer survivorship care. And equally important, the survivors need to know what their responsibilities are in self-management. A survivorship care plan provides that road map, outlines what tests are to be done, who orders them, when, and why. It also includes what other surveillance tests or exams should take place going forward. There is also a section associated with adopting healthier lifestyle behaviors, with the goal of reducing the risk of recurrence of their cancers as well as reducing the risk of getting a new primary cancer of a different kind. The management of side effects also is

included so that measures taken to diminish them are done in a way that doesn't negatively impact their cancer risk in the future. (For example, a breast cancer survivor should never be prescribed hormone replacement therapy for control of hot flashes and night sweats as it could increase her risk of recurrence. And if she is receiving hormonal therapy, it will undo the benefits of taking the medication designed to prevent recurrence.) There should also be a summary of potential late effects that a survivor may develop years or even decades down the road that actually result from the cancer treatment they just completed with you. PCPs need to understand this as well to prevent the assumption that what they are seeing is an early onset of cardiac disease when it could very well be a late effect of cardiotoxicity associated with a chemotherapy drug.

In this issue you will find 2 different perspectives regarding survivorship care plans: one from a nurse and the other from a pharmacist. Their input and understanding is enlightening and valuable to read.

So, as you see your next newly diagnosed cancer patients, begin establishing expectations early on. The goal after all is for the patients to never need you again once their cancer treatment is completed. Help them embrace survivorship, take charge of their health and their life again, and follow the road map you have built for them. And remember, your ultimate goal for the patients is that they will never need you again. ■

## The Importance of Cancer Survivorship Care Plans: A Pharmacist's Perspective

Steve Stricker, PharmD, MS, BCOP

*LM is a 35-year-old female who was diagnosed with Hodgkin lymphoma and treated with ABVD (doxorubicin, bleomycin, vinblastine, and dacarbazine) in 2009. Radiographic scans completed at the conclusion of therapy demonstrated that LM had achieved a complete response. Two years later, LM presented to our clinic complaining of generalized fatigue ongoing for the past 2 to 3 weeks. A complete blood count revealed an elevated white blood cell count, and findings from a bone marrow biopsy were consistent with acute myeloid leukemia (AML), likely associated with her prior exposure to chemotherapy.*

In our community cancer center, identifying and diagnosing a second malignancy in a patient like LM is highly unusual. However, as one of a constellation of known survivorship issues in patients treated with chemotherapy and/or radiation therapy, we teach pharmacy students and medical residents training at our site to internalize a philosophy of “pattern recognition.” This idea suggests that any patient returning for a routine follow-up/monitoring visit is comprehensively assessed not only for recurrence of their malignant disease (eg, the pattern of where that disease may likely spread via metastasis) but also for chronic issues that may stem from their prior therapy. While secondary malignancies may be rare, issues such as cardiotoxicity, hypothyroidism, infertility, neurocognitive deficits, depression, anxiety, peripheral neuropathy, etc, are observed with greater frequency and are often better identified and managed when multiple providers are involved in a multidisciplinary approach to cancer care.

Because many of the most common cancers are diagnosed in the sixth to eighth decade of life, historic data on survivorship issues were predominantly generated from long-term monitoring of pediatric cancer patients surviving into adulthood. However, as the body of knowledge related to cancer biology has grown and new drugs for cancer have continued to find their way into clinical practice, cure rates and overall survival for adult cancer patients have increased over the past few decades. The result is an

increasing number of patients alive for whom survivorship issues are relevant, necessitating ongoing monitoring and possibly requiring intervention. In fact, it is estimated that as of 2009 there were 363,000 survivors of childhood cancer in the United States.<sup>1</sup> Combine this statistic with data from the American Cancer Society estimating that from 1971 to 2012 the overall number of cancer survivors grew from 3 million to 13.7 million and is projected to increase to 18 million by 2022, and survivorship concerns become a major problem that the oncology community must accept and adapt to and comprehensively address.<sup>2,3</sup>

As oncology providers, we must first recognize that not all survivorship issues are created equally. In 1985, an often-cited landmark report on cancer survivorship was published in which physician Fitzhugh Mullan described his own battle with cancer and the unique issues that lay ahead for survivors of malignancies. Writing from a personal perspective, he identified 3 “seasons of survival” for cancer patients: acute survival, defined as the time from new diagnosis through completion of initial treatment; extended survival, describing the time during which patients experience anxiety related to the possible recurrence of their disease, often beginning with the end of initial treatment; and permanent survival, when the patients recognize the likelihood of being cured of their disease.<sup>4</sup> While Mullan’s words are now nearly 30 years old, they still provide guidance to us today.

We will focus our discussion on late effects encompassing both chronic health conditions and severe or life-threatening problems (Mullan’s permanent survival period), as it has been estimated that as many as 50% of survivors experience such issues.<sup>5</sup> As a clinical oncology pharmacist charged with monitoring and educating cancer patients about their drug therapy, I take survivorship issues personally since it is generally understood that the chemotherapy and/or radiation therapy we use every day is responsible for these dreadful chronic issues.

As in the case of LM, we identified that secondary



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malignancies are uncommon yet account for as much as 16% of all cancer diagnoses.<sup>6</sup> Furthermore, the risk of a cancer survivor developing a secondary malignancy is 10-fold higher than in the general population.<sup>1</sup> Certain patterns emerge when we look more closely at this small yet important cohort of cancer patients. Hematologic secondary malignancies such as AML have been associated with the use of alkylating agents (in our example, LM was exposed to dacarbazine) and/or topoisomerase II inhibitors. Characteristic cytogenetic abnormalities involving chromosomes 5 or 7 in the case of alkylating agents or chromosome 11q23 in the setting of topoisomerase II inhibitors should be investigated in patients previously treated

treatment and their ability to inform other healthcare providers of their total anthracycline dose.<sup>1</sup>

There are many other well-defined examples that could be cited here to illustrate the importance of aggressively monitoring cancer survivors, early identification of these survivorship issues, and early intervention when issues arise. Cancer centers on the cutting edge of survivorship management focus on the creation of survivorship care plans in an attempt to minimize the possibility that patients are lost to follow-up or receive anything less than optimal long-term monitoring and care. These care plans often comprehensively include the specific type of cancer the patient was diagnosed with, the drug therapy plan complete with drug doses, any toxicities the patient experienced during treatment, and any long-term issues experienced by the patient. Furthermore, this care plan should identify which providers are to be involved in the patient's ongoing care as well as a schedule for monitoring and assessment.<sup>9</sup>

Even with the recognized importance of cancer survivorship issues and the development of survivorship care plans, patients still fall through the proverbial cracks in the healthcare system. Cheung and colleagues reported in 2009 the results of a study evaluating patient and physician expectations of survivorship care. Among the observations in this report is that patients exclusively monitored by primary care physicians underwent "fewer screening tests for cancers, whereas those assessed predominantly by oncologists receive less than recommended noncancer-related care."<sup>10</sup> Current medical practices may not adequately define the best collaboration of providers to ensure the patient's total care is appropriately addressed. Most certainly there is room for improvement in this area!

Once again, we return to the idea of the multidisciplinary nature of modern oncology medicine. In the accompanying article, Beth Faiman discusses the role of nurses in identifying and referring patients to survivorship programs. Our nurses and nurse practitioners are also engaged in this role, which complements and enhances our team approach to these patients. Pharmacists, including myself, frequently find themselves in a role of patient education, monitoring, and direct management of supportive care issues. Perhaps the greatest contribution in the setting of cancer survivorship is the aspect of patient monitoring. Upon return to the clinic, even years after completion of therapy, I closely review the patient's drug therapy, exposure to radiation therapy (if applicable), and make recommendations to our oncology team related to oversight of these real or potential long-term complications of cancer treatment. An additional role of the oncology

## Current medical practices may not adequately define the best collaboration of providers to ensure the patient's total care is appropriately addressed.

with these agents. Some commonly observed solid secondary malignancies include breast, lung, and thyroid cancers and brain tumors.<sup>1</sup> This latter group of cancers are often related to a patient's previous exposure to radiation therapy. This explains the increased incidence of medial lung and breast cancers diagnosed in patients who received mantle radiation, most often in the setting of mediastinal tumors associated with Hodgkin lymphoma. Latency periods for hematologic secondary malignancies are often 5 to 10 years versus a longer time for solid secondary malignancies, thus creating a compelling case for indefinite oncologist oversight of these patients.<sup>7</sup>

Perhaps the most well-characterized chemotherapy-related survivorship issue is the development of cardiovascular disease associated with anthracycline exposure. Patients beginning therapy with these agents often, if not always, undergo assessment of their left ventricular ejection fraction by echocardiogram or multigated acquisition scan. Additionally, cumulative exposure to an anthracycline is closely monitored to ensure patients do not exceed well-established lifetime maximum doses. Data from long-term monitoring of adult survivors of pediatric malignancies reveal a 15-fold increase in the risk of developing congestive heart failure (CHF) compared with age-matched controls.<sup>8</sup> Overall survival in patients who develop CHF in this setting is less than 50% at 5 years and argues for the importance of patients understanding the risks of

pharmacist involves ongoing patient education. Some may wrongly assume that patient education related to chemotherapy is an acute issue undertaken and often forgotten after the patients begin their initial therapy. However, studies have suggested that only 72% of patients can accurately report their precise cancer diagnosis, 52% of patients receiving anthracycline-based therapy with doxorubicin could report their dose exposure, and 70% of childhood cancer survivors could appropriately report the anatomic site treated with radiation therapy.<sup>7</sup> If patients are to be empowered to advocate for their own healthcare, they need to be re-educated about key factors that may contribute to chronic survivorship issues so that these can be reported to future healthcare providers.

In the case of LM, her response to therapy for AML was poor, and she succumbed to her disease within a period of months following diagnosis. Despite her poor outcome, tremendous hope can now be identified in patients who live longer, better, and are more frequently cured than ever. While our focus never deviates from our established goals of cancer treatment, we must not lose sight of the patient's overall health in an ongoing manner. For this, all members of the oncology healthcare team *must* be educated on survivorship issues, *must* be comfortable in proactively discussing these issues with patients, and *must* be actively in-

volved in ensuring a patient's ongoing access to care. Each patient diagnosed with a chronic survivorship issue that might have been mitigated through monitoring or aggressive intervention represents a failure of the oncology system. Such failures cannot be accepted as more and more patients will become cancer survivors over the decades to come. ■

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## The Importance of Cancer Survivorship Care Plans: A Physician's Perspective

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In 2005, the Institute of Medicine released a report with a title that became a wake-up call for many in the field of oncology, *From Cancer Patient to Cancer Survivor: Lost in Transition*. A committee of 17 experts in the field set out to raise awareness of the consequences of having cancer and cancer treatments, to define a standard of healthcare quality for cancer survivors, and to determine how to implement that quality and to improve the quality of life of cancer survivors.<sup>1</sup> In the 8 years since this report, there has been some progress toward these goals but arguably not enough. Many large and small oncology centers and practices have developed survivorship programs, but there are many uncertainties regarding how best to integrate such programs with existing oncology follow-up. Transition of patients or comanagement of patients with other providers, including their primary care physician, remains a challenge in terms of defining the roles of each provider in the overall care of the patient. Oncology practices are starting to develop treatment summaries and surveillance outlines, but they remain a minority. Research in survivorship remains a very small slice of the overall dollars devoted to cancer funding.

Beth Faiman's article raises a very important point with her discussion of who is a survivor. Without a definition, it is hard to focus the energies needed to improve the "lost in transition." Some define survivor broadly, beginning with the day the patient is diagnosed. Others define it as the period when treatment ceases and there is no evidence of disease. And there are gray areas in between. Regardless of the definition, car-

ing for the cancer survivor is complex and requires a team approach. Within that team, the roles of each provider need to be defined to achieve the health maintenance that Ms Faiman outlines in her perspective.

Steve Stricker's article focuses on the need to follow cancer survivors for late effects of therapy. I would add to this argument that this is where research is so far behind in the continuum of our understanding of cancer. The article mentions the cardiovascular effects of anthracycline exposure. This toxicity has been known for many years. While there are data on the timing of such effects and the cumulative dose of drug that substantially impacts the risk, little is known about which patients get such toxicity or how to avoid it. Such lack of research is common for most late side effects of cancer therapy. We have

reasonably good data on the percentage of patients impacted and when the late effect is seen, but beyond that there are huge research needs in the field.

Ten years ago, a series like *Conquering the Cancer Care Continuum* may not have included survivorship as a topic. Thus, having the perspectives by Beth Faiman and Steve Stricker in this series is a clear reflection that progress has started. However, we all still remain a bit lost on the issue and should work together to improve our understanding and our care of the increasing proportion of our population that are cancer survivors. ■

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