

PERSPECTIVE

Cancer Survivorship Care: Exploring the Role of the General Internist

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According to the National Cancer Institute (NCI), cancer survivorship encompasses the “physical, psychosocial, and economic issues of cancer from diagnosis until the end of life.” Today, one in 30 Americans are cancer survivors. Almost two-thirds have at least one chronic health condition. As the numbers of cancer survivors increase, cancer itself can be viewed as a chronic medical condition. This paper illustrates some of the challenges faced by cancer survivors. We discuss the limitations of current models of survivorship care, including shared care. In addition, we explore how the American Board of Internal Medicine’s previously proposed credential of Comprehensive Care Internist could serve to define and integrate the complex needs of adult cancer survivors with the skills and talents of general internists.

KEY WORDS: cancer survivorship; comprehensive care internist; shared care.

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The effect of cancer extends far beyond the diagnosis and treatment period. Compared to individuals without a history of cancer, cancer survivors have more functional limitations and more psychosocial problems, and they are more likely to lack health insurance (Table 1).^{1,2} Furthermore, therapies used for cancer treatment can have associated toxicities, including the development of secondary cancers, chronic medical conditions, and poorly understood health effects (Table 2).^{2–6} For example, persistent difficulties with memory and concentration have been reported in up to one-third of patients with breast cancer receiving chemotherapy.^{7,8} Recent studies suggest a link between neurocognitive dysfunction, commonly referred to as “chemo brain”, and cancer treatment.^{7–9} Another example includes the association between cisplatin-based chemotherapy and increased rates of cardiovascular disease, possibly due to cisplatin-induced endothelial damage.¹⁰ Because of an increase in the recognition of the unmet needs of cancer survivors, the Institute of Medicine (IOM) published *From Cancer Patient to Cancer*

Survivor: Lost in Transition in 2005.¹¹ The report identified four essential components of survivorship care:

1. “Prevention of recurrent and new cancers, and other late effects;
2. Surveillance for cancer spread, recurrence, or second cancers; assessment of medical and psychosocial late effects;
3. Intervention for consequences of cancer and its treatment;
4. Coordination between specialists and primary care provider to ensure all aspects of the survivor’s health needs are met.”¹¹

Barriers identified in the IOM report included a fragmented and poorly coordinated healthcare delivery system, few evidence-based guidelines on follow-up care for cancer survivors, and a lack of education and understanding by healthcare professionals of survivorship issues.¹¹ To address these barriers, the IOM’s Committee on Cancer Survivorship made a number of recommendations including calls for program support to test models of coordinated, interdisciplinary survivorship care.¹¹ Currently, a few such models exist across the country. Although an important start, these programs are too few in number to reach many cancer survivors. Furthermore, cost-effectiveness studies are lacking and still need to be conducted. It is also unclear how the complex and poorly understood interactions of chronic disease and cancer will be addressed by these models. This paper explores ways in which general internists could integrate existing skills in chronic disease management with cancer survivorship to provide comprehensive care to large numbers of adult cancer survivors.

CARE MODELS

First established in the 1980s, programs that deliver follow-up care for adult survivors of pediatric cancers provide the most information on survivorship care.¹² Rather than being disease specific, pediatric long-term survivorship programs follow survivors of all childhood cancers. Care is usually led by a pediatric oncologist and provided in a multidisciplinary setting with ancillary support, including a social worker and psychologist. The goals of the follow-up program are to provide coordinated, multidisciplinary care addressing cancer-related psychosocial issues; evaluate for disease recurrence, second malignancies, and treatment-related toxicities; and provide education and counseling on health maintenance.

Table 1. Self-reported Information among Persons with and Without a Cancer History

Self-reported information	Cancer history		No cancer history		p<0.001
	(n = 4878)		(n = 90737)		
By ages (years)	n	%	n	%	
Smokers with cardiovascular disease					*
18-44	517	(10.6)	3992	(4.4)	
45-64	1004	(20.6)	12340	(13.6)	
65+	1917	(39.3)	30124	(33.2)	
Fair to poor health					*
18-44	897	(18.4)	4718	(5.2)	
45-64	1453	(29.8)	12521	(13.8)	
65+	1668	(34.2)	21958	(24.2)	
≥ 3 Medical problems†					*
18-44	73	(1.5)	18147	(0.2)	
45-64	151	(3.1)	1179	(1.3)	
65+	190	(3.9)	2086	(2.3)	
Reported psychological problems					*
18-44	448	(9.2)	2540	(2.8)	
45-64	297	(6.1)	2812	(3.1)	
65+	175	(3.6)	2268	(2.5)	
Inability to work due to health					*
18-44	253	(11.6)	2540	(2.8)	
45-64	965	(19.8)	8257	(9.1)	

Data adapted from the National Health Interview Survey.²

*p<0.001 for all ages (comparison of patients cancer history and patients with no cancer history)

†As reported to respondents by a physician (cardiovascular disease, emphysema, asthma, diabetes, kidney disease, liver disease)

Two broad types of adult survivorship follow-up clinics exist (clinical and consultative) at a number of NCI-designated Comprehensive Cancer Centers (CCCs) (Appendix A).¹³ Although variations in implementation exist, the clinical model most resembles the pediatric cancer follow-up care model. Cancer survivors are referred to the follow-up clinic at some predetermined time (e.g., 2 years after completion of treatment). Care is then provided by a clinician, usually a nurse practitioner, working with the cancer specialist. In the consultative model, referral usually occurs at the end of the active surveillance period (e.g., 5 years after diagnosis). In each model, a comprehensive care plan, including follow-up recommendations, is provided and access to a multidisciplinary care team is available. Both models strive to coordinate follow-up care with a primary care physician (PCP).

Only about 15% of patients with cancer receive their care at an NCI-designated cancer center (Appendix B).¹¹ Most patients with cancer receive care within the community where survivorship services may include group and web-based resources and ancillary clinics, such as nutrition support and physical therapy. Some community programs may have survivorship follow-up clinics but formal data are lacking.

Multidisciplinary adult survivorship follow-up clinics are resource intensive and require ancillary support, which may not be reimbursed by third-party payers. The shared care model of chronic disease management has been proposed as an alternative mechanism for providing survivorship care.¹² Rather than a formal survivorship follow-up clinic, this model focuses on coordination of care by clinicians in different specialties (e.g., PCPs and oncologists). Essential components of shared care include frequent information exchange, clear delineation of responsibilities, and agreement on care goals by members of the

treatment team. This approach has greater reach and is reasonable for many cancer survivors at low risk for disease recurrence with few medical problems. However, the implementation of shared care for adult cancer survivors with complex medical issues or those who have undergone complicated, multimodal therapy is likely difficult. Individuals with chronic health conditions are among the least well-studied group of cancer survivors.¹⁴ Thus, much has yet to be learned about the interactions among cancer, cancer treatment, and chronic disease, making clear delineation of responsibilities and agreement on care goals difficult. In addition, a rapidly expanding list of cancer therapeutic agents and a lack of evidence-based guidelines in follow-up care for cancer survivors further complicate delineation of responsibilities, and agreement on care goals. Existing barriers of medical information exchange (such as the lack of electronic medical records at many medical centers) make transfer of information between cancer specialists and PCPs even more critical. When information exchange is less than optimal, the burden of health history communication falls almost entirely on the patients who may have little knowledge about the specific details of their cancer stage and treatment. Thus, shared care is only possible when patients have an established relationship with a PCP. For individuals without a PCP, the cancer specialist is obligated to provide ongoing care, including routine preventative healthcare, until a relationship with a PCP has been established. Given the current and expected shortages of both cancer specialists and PCPs, such coordinated care may not always be possible.^{15,16}

Although many cancer survivors in the United States see both a cancer specialist and PCP, few studies of these "shared care" examples have been done. Evidence from these studies, however, suggests that basic components of shared care are

Table 2. Examples of Delayed Treatment-associated Organ Effects

Organ	Toxicity	Associated agents
Cardiac	Congestive heart failure	Anthracyclines (e.g., doxorubicin) Rates increase further out from treatment (reported up to 25 years) Irreversible systolic and diastolic dysfunction Risk increases with increasing dose younger age at treatment Trastuzumab Reversible, not dose dependent Long-term studies lacking Radiation* –largely diastolic dysfunction Radiation*
	Conduction problems (AV block, BBB) Pericardial disease	Radiation* Presents months to years later May progress to chronic constrictive pericarditis Radiation* (AI most commonly seen)
	Valvular Atherosclerosis	Cisplatin- Endothelial damage May also increase risk of traditional heart disease risk factors (e.g., lipid problems and obesity) Radiation* (RCA more commonly involved) Radiation*
Pulmonary	Pneumonitis (1–3 months after therapy)	Radiation* Risk highest for external beam radiation for lung cancer Bleomycin- Usually acute but there are reports as late as 2 years after therapy Risk increases with concurrent use of radiation Radiation*
Nervous system	Pulmonary fibrosis Neuropathy	Taxanes (e.g., docetaxel, paclitaxel)
Other	Leukemia Premature Menopause Lymphedema	Alkylating agents Alkylating agents Especially with both axillary node dissection and radiation

AV atrioventricular, BBB bundle branch block, AI aortic insufficiency, RCA right coronary artery
***Radiation toxicity significantly reduced after 1985.**

lacking. For example, a recent survey revealed discrepancies in perceived responsibilities among healthcare professionals (PCPs and oncologists) including areas of follow-up for cancer recurrence and general preventative health.¹⁷ In addition, cancer survivors in this study were also uncertain as to the duties and responsibilities of their healthcare providers.¹⁷

A further challenge to the implementation of shared care relates to the increasing time pressures faced by both PCPs and cancer specialists. In the shared care model as outlined by Oeffinger and McCabe, after the period of active surveillance, the primary responsibility for addressing the physical and emotional well being of cancer survivors falls on the PCP.¹² This may require ancillary services not readily available. Current studies demonstrate that PCPs lack the time needed to provide necessary preventative and chronic disease care.^{18,19} Thus, it is difficult to envision these clinicians being able to provide comprehensive survivorship care in the traditional 15-minute office visit.

ARGUMENT FOR THE ROLE OF GENERAL INTERNIST

Although a recent Cochrane review found little evidence supporting shared care in chronic disease management, results from studies conducted in the United States demonstrate that specialty care is more effective when patients have an ongoing relationship with a PCP.^{16,20} Furthermore, evidence exists that indicates greater involvement by PCPs is currently needed for cancer survivors. For example, necessary preventive healthcare screen-

ing may be lacking for cancer survivors. A 2004 study of 14,884 Medicare-eligible nonmetastatic colon cancer survivors (beyond 5 years) compared the level of chronic care received by cancer survivors versus matched control subjects.²¹ Compared to matched control subjects, diabetic colon cancer survivors were less likely to receive routine eye exams and have their glycosolated hemoglobin (HgbA1c) monitored. They were also less likely to have their lipid profiles evaluated within 1 year of receiving an angina diagnosis. Survivors who saw both a PCP and cancer specialists, however, received the highest level of recommended care.²¹ Similarly, a study using the Surveillance, Epidemiology and End Result (SEER)-Medicare database of breast cancer survivors found that survivors who saw both a PCP and an oncologist were more likely to get recommended care.²²

Empiric data in the United States provides evidence that general internists are already playing a role in providing cancer survivorship care. Data from the National Ambulatory Care Medical Survey (NAMCS) and the National Hospital Ambulatory Care Survey (NHACS) compiled from 2001 and 2002 revealed that about 47% of adult cancer patients had their cancer care shared between a cancer specialist and at least one other physician, and 32% of all cancer-related adult ambulatory care visits occurred with a PCP.¹¹ However, given the high rates of chronic disease among cancer survivors, the poorly understood interactions among cancer, cancer treatment, and chronic disease, and the increasing number of cancer survivors, general internists will likely be playing a larger role in cancer survivorship care.

Adult survivors of cancers (both childhood and adult) have higher rates of chronic diseases. For example, compared to siblings without a cancer history, cancer survivors in the Childhood Cancer Survivor Study had a 3-fold increased risk for developing a chronic medical condition (RR=3.3; CI, 3.0 to 3.5).⁵ Similarly, adults with a cancer history in the National Health Interview Survey reported more chronic medical conditions compared to individuals without a previous cancer history.² (Table 1) In other examples, chronic conditions may increase the risk for cancer development such as the association between diabetes and increased risk for breast cancer.²³⁻²⁵ The increased rates of chronic disease may be due to the cancer, cancer treatment, and underlying risk factors for cancer development. Thus, survivorship care for many adult cancer survivors will involve more than surveillance for disease recurrence and second cancers. For these individuals, the delivery of coordinated, collaborative, and multidisciplinary care, led by a healthcare provider with expertise in addressing the complex needs of adult cancer survivors will become increasingly more important. General internists, already adept at caring for adults with complex health issues, are particularly well suited in leading cancer survivorship care.

In recognition of the growing complexity of our aging population, the American Board of Internal Medicine (ABIM) had proposed in 2007 the new credential of "Internal Medicine with Focused Practice in Comprehensive Care." They define Comprehensive Care Internal Medicine (CCIM) as *the personal, longitudinal and coordinated care-including prevention and wellness care for a defined population of patients with undifferentiated, acute and/or chronic problems.*²⁶

We feel that the establishment of a CCIM credential in cancer survivorship care is worth reconsideration. This credential would take into account the complex challenges seen in cancer survivorship. For example, few evidence-based guidelines on follow-up care for cancer survivors exist, especially pertaining to follow-up care for delayed treatment-related effects (e.g., monitoring for cardiac toxicity from doxorubicin). In other examples, cancer survivors may choose to undergo genetic testing, the results of which may further complicate issues of surveillance and risk management (e.g., increased risk for pancreatic cancer among carriers of the BRCA2 gene mutation²⁷). Therefore, we recommend that the CCIM credential be established as an option for general internists choosing to lead cancer survivorship care. This distinction should involve both title and remuneration. Although we feel that a set of core competencies in knowledge, skills, and attitudes of cancer survivorship should be possessed by all PCPs, professional organizations such as the American College of Physicians should establish additional competencies for the internist practicing CCIM in cancer survivorship. All PCPs should have an understanding of the broad range of health effects from cancer and cancer treatment. The general internist practicing CCIM, however, would possess knowledge pertaining to the potential short- and long-term health effects of specific cancer treatments, especially as they relate to chronic medical conditions. In addition, the general internist practicing CCIM in cancer survivorship would be familiar with the management of treatment-related side effects. For example, whereas all PCPs should be aware of joint pain experienced by patients on aromatase inhibitors, the general internist practicing CCIM would be comfortable in managing these side effects. Whereas

all PCPs should be aware of evidence-based surveillance and screening recommendations for cancer survivors, the general internist practicing CCIM would be aware of consensus-based recommendations made by professional organizations such as the American Society of Clinical Oncology. Thus, the general internists practicing CCIM would be uniquely positioned to provide comprehensive, risk-based, follow-up survivorship care.

Skills in communication and coordination are critical to providing care for all patients. When patients are transitioned back to their PCP, relevant information on the cancer survivor's history, treatment regimens, adverse effects, and individualized follow-up recommendations need to be clearly communicated between the cancer specialist and the PCP. For some patients, however, active and early involvement by general internists may be particularly beneficial (e.g., patients with poorly controlled diabetes undergoing chemotherapy). Thus, we envision the general internist practicing CCIM to serve as the care coordinator for cancer survivors with complex health needs even during their active treatment period.

As with all PCPs, professional attitude should incorporate behaviors and qualities of the highest standards essential to delivering comprehensive, outstanding, patient-centered care. A locus of responsibility is essential for care of all patients with chronic diseases. Similar to the hospitalist model, the internist practicing CCIM in cancer survivorship could serve as the care coordinator and advocate in situations where a PCP is lacking or when active involvement is requested by the PCP. They would be willing to consult in areas of chronic disease management for the cancer specialist and cancer survivorship for the PCP. In addition, internists practicing CCIM would be willing to investigate unanticipated side effects from cancer and cancer treatments, possess the ability to work effectively with a multidisciplinary care team, and work with professional organizations to establish evidence-based guidelines for follow-up care.

CONCLUSION

Of the 1 in 30 Americans who are cancer survivors, almost two-thirds have at least 1 chronic health condition. As our population ages, this figure is expected to increase dramatically over the next several decades. As seen from follow-up data for adult survivors of childhood cancers, much of the long-term effect of cancer and cancer treatment presents decades after completion of therapy. Thus, the complex interactions of cancer, cancer treatment, and chronic disease, therefore, will become an increasingly important challenge for all healthcare providers. To meet this challenge, increased emphasis must be placed on survivorship care by professional organizations and third party payers. While all PCPs will need to have an increased understanding and awareness of cancer survivorship care, we feel that the complex interactions of cancer, chronic disease, and cancer treatment will likely benefit from active involvement by general internists. We recognize that many questions and concerns surround proposals for additional certification, however, we feel that cancer survivorship is uniquely complex and deserves consideration for such certification. The ABIM's proposed credential of Comprehensive Care Internists could serve to recognize general internists choosing to meet the challenges of cancer survivorship care and potentially improve the overall quality of care delivered to cancer survivors.

Conflict of Interest: None disclosed.

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APPENDIX A: NCI -DESIGNATED CCC WITH AT LEAST ONE ADULT SURVIVORSHIP FOLLOW-UP CLINIC.** (INFORMATION LAST ACCESSED FROM WEBSITES APRIL 1, 2009)

Center Name

- *Abramson Cancer Center-University of Pennsylvania
http://pennccancer.org/cancerprograms_detail2.cfm?id=32&w=about
Case Comprehensive Cancer Center
<http://www.uhhospitals.org/irelandcancer/tabid/1883/Default.aspx>
City of Hope
<http://www.cityofhope.org/about/publications/hope-news/2008-vol-3-num-20-june-30/Pages/prostate-cancer-survivorship-clinic-opens-doors.aspx>
- *Dana Farber Cancer Institute
<http://www.dana-farber.org/pat/surviving/default.html>
- *Fred Hutchinson Cancer Research Center
<http://www.fhcr.org/science/clinical/ltfu/>
+MD Anderson
<http://www.mdanderson.org/topics/survivorship/display.cfm?id=27f0b87c-175f-441e-91b2dbaa58d6302b&method=displayfull>
- *Memorial Sloan-Kettering Cancer Center
<http://www.mskcc.org/mskcc/html/64918.cfm>
Norris Cotton Cancer Center
Dartmouth-Hitchcock Medical Center
<http://www.cancer.dartmouth.edu/survivorship/index.shtml>
- *Ohio State University Comprehensive Cancer Center
<http://www.jamesline.com/patientsandvisitors/survivorship/>
- *UCLA's Jonsson Comprehensive Cancer Center
<http://www.cancer.ucla.edu/Index.aspx?page=590>
- *University of Colorado Cancer Center
<http://www.uccc.info/conditions/cancer/survivorship-clinics/adult-survivors-clinic/adult-cancer-survivors-clinic.aspx>
- *University of North Carolina Lineberger Comprehensive Cancer Center
<http://cancer.med.unc.edu/patient/support/clinics.asp>
Vanderbilt-Ingram Cancer Center
<http://www.vicc.org/news/?p=445>
Yale Cancer Center
<http://www.yalecancercenter.org/surviving/challenge.html>

* Receives financial support from Lance Armstrong Foundation
**Since formal published information on adult survivorship clinics for the 2009 NCI-CCCs is lacking, information was obtained from individual center's website. Centers had to have a description of a follow-up program on their website that provided individualized follow-up care by a health professional (MD or NP) and provide access to a multidisciplinary team for adult survivors of adult cancers.
+ General Internal Medicine Involvement Specified at Cancer Center

APPENDIX B: TYPES OF CANCER PROGRAMS IN US

NCI-designated	(N=63)	Goals selection process
Comprehensive cancer centers (N=40)	Research* Provides clinical care outreach and education	Application/NCI- approval
Cancer centers (N=23)	Research* +/-Provides clinical care	Application/NCI- approval
Community cancer centers** (N=16)	Pilot study	Application/NCI approval
American College of Surgeon's Commission on Cancer [^] (N=1433)	Clinical care	Application/approval
Association of Community Cancer Centers [*] (N=650)	Clinical care	Membership application

* Basic science, population, and clinical

**Purpose is to expand cancer research and increase access to advanced cancer care

[^] <http://www.facs.org/cancer>

^{*} <http://accc-cancer.org/>