

Cancer Survivorship Care: Instructions Not Included!

University of Texas Southwestern Medical Center

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Purpose and Overview:

Cancer survivors constitute a rapidly expanding part of the US population. Considering the long-term and late effects of cancer / cancer treatment, care of cancer survivors poses a public health challenge. Existing and emerging data suggest significant gaps in knowledge, research, and care of cancer survivors. Despite efforts by professional organizations, government agencies and patient advocacy groups over the past 3 decades, cancer survivorship care remains fragmented and often inadequate.

This review is intended to raise healthcare providers' awareness of the unique needs of cancer survivors, and challenges in implementation of cancer survivorship programs.

Educational Objectives:

Understand cancer survivorship and its public health implications

Recognize late and long-term effects of cancer treatment

Apply basic concepts of cancer survivorship into patient care

Definitions:**Survivor:**

The term “*Cancer Survivor*” is often thought to imply curative intent treatment and achieving a remission. The National Coalition for Cancer Survivorship, an advocacy group founded in 1986, offers a more inclusive definition for survivorship as “the experience of living with, through, and beyond a diagnosis of cancer”. This definition has been adopted by all professional cancer organizations and patient advocacy groups, including the Office of Cancer Survivorship at the NCI:

“An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. Family members, friends, and caregivers are also impacted by the survivorship experience and are therefore included in this definition”

Long-term and late effects of cancer treatment [1]:

All forms of cancer treatment can have unwanted, long-term and late effects on tissues and organ systems that impair a person’s health and quality of life in small and large ways. Early, or short term, side effects – such as chemotherapy induced nausea – are not discussed in this presentation.

Long-term effects refer to any toxicity or complication of treatment – for which a cancer patient must compensate – which begins during treatment and continues beyond the end of treatment. Chemotherapy induced neuropathy is an example of long-term effects of cancer treatment.

Late effects refer to toxicities that are absent or unnoted (subclinical) at the end of therapy and become manifest later with the unmasking of previously unrecognized injury by any of the following factors: developmental processes; the failure of compensatory mechanisms with the passage of time; or organ senescence. Late effects appear months to years after completion of treatment. Heart failure due to radiation and/or chemotherapy is an example of late effects of cancer treatment.

Epidemiologic and public health considerations:

The lifetime probability of being diagnosed with invasive cancer in the US is one in 3 (39.3% in men and 37.7% in women) [2]. Despite the overall declining incidence rates of cancer in men and stable rates in women, the number of cancer survivors in the US has been consistently rising. This is largely due to a combination of increased screening and early detection, as well as more aggressive/better treatments resulting in improved outcomes (decreasing cancer mortality).

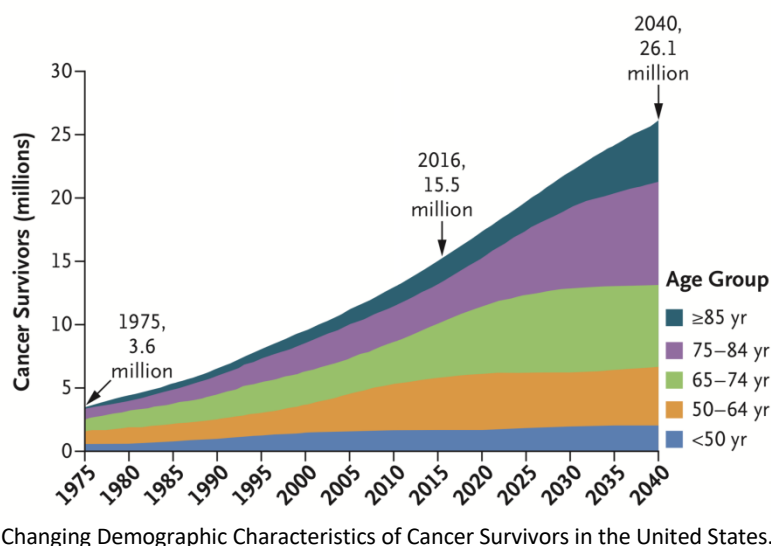
Considering the unique healthcare challenges of cancer survivors, the American Cancer Society in collaboration with the National Cancer Institute began to estimate and report the numbers of current and future cancer survivors biennially to inform care delivery, research, and policy.

Based on this report, the number of cancer survivors in the US in 2019 is estimated at 16.9 million; this number is expected to reach 22.1 million in 2030 and 26.1 million in 2040 [3].

As of January 1, 2019	Male		 	Female	
	Prostate	3,650,030		Breast	3,861,520
	Colon & rectum	776,120		Uterine corpus	807,860
	Melanoma of the skin	684,470		Colon & rectum	768,650
	Urinary bladder	624,490		Thyroid	705,050
	Non-Hodgkin lymphoma	400,070		Melanoma of the skin	672,140
	Kidney & renal pelvis	342,060		Non-Hodgkin lymphoma	357,650
	Testis	287,780		Lung & bronchus	313,140
	Lung & bronchus	258,200		Cervix	283,120
	Leukemia	256,790		Ovary	249,230
	Oral cavity & pharynx	249,330		Kidney & renal pelvis	227,510
	All sites	8,138,790		All sites	8,781,580

FIGURE 1. Estimated Number of US Cancer Survivors by Site. Estimates do not include in situ carcinoma of any site except urinary bladder and do not include basal cell or squamous cell skin cancers.

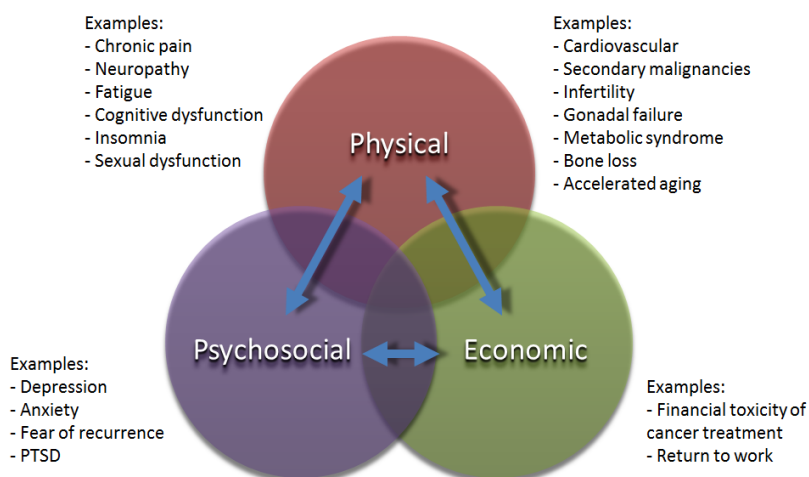
Nearly two third of the survivor population in the US are aged 65 years and older [4-5]. This fact merits attention as higher prevalence of chronic conditions in this age group further adds to the complexity of their care [6].



Late and long-term effects of cancer treatment [5]:

Late and long-term effects of cancer treatment can be divided into three domains: physical, psychosocial, and economic. It is important to recognize not only the overlap, but also the interaction between these domains. As an example, depression may interact with chronic fatigue and both may affect the ability of the individual to return to work which in turn may prevent access to care due to cost. Without appropriate care, individual's symptoms may worsen, thus creating a vicious cycle.

Late and long-term effects of cancer treatment



Physical well-being in cancer survivors:

Late and long-term “physical” effects of cancer treatment range from life threatening conditions such as secondary malignancies, to symptoms that can impair the individual’s function and quality of life, for example cognitive impairment.

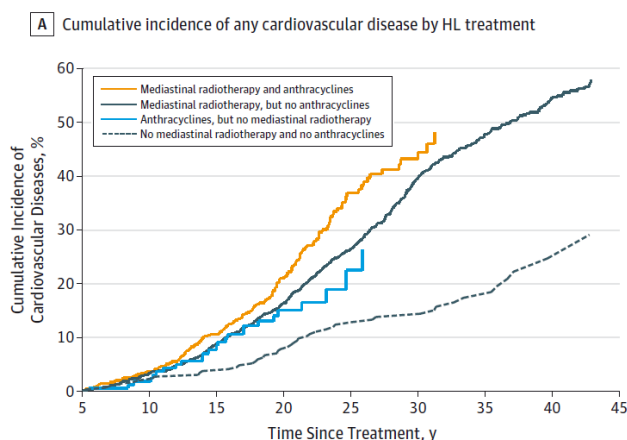
By mid 1980s, excess mortality was recognized in both pediatric and adult cancer survivors. Late treatment effects with an impact on survival are best demonstrated in Hodgkin lymphoma (HL) studies. HL is one of the first malignancies where cure became possible by using multi-agent chemotherapy regimens/combined modality treatments (systemic therapy and radiation). Studies on long-term survivors have shown that despite successful treatment of pediatric HL, the mortality rate is higher than control populations. Causes of excess mortality, aside from HL (primary cancer), include cardiac disease, infections, and second neoplasms [7]. Concordant results were reported in survivors of adult HL [8]. These observations are not unique to HL, which further underscored the significance of late effects of chemotherapy, in particular cardiovascular effects and subsequent primary cancers.

Cardiovascular late effects of cancer treatment [9]:

Treatment with anthracyclines such as doxorubicin is the most recognized cause of late cardiac toxicity, causing irreversible myocardial damage. Radiation therapy can induce inflammation, oxidative stress, endothelial dysfunction, damage to the microvasculature, accelerated atherosclerosis, myocardial damage, valvular disease, and conduction abnormalities. Cardiomyopathy from targeted therapies against HER-2 receptor is generally considered to be clinically reversible. Anti-androgen/anti-estrogen agents do not cause direct toxicity to the heart; however, they can increase the risk of cardiovascular events through intermediary mechanisms such as dyslipidemia,

metabolic syndrome, etc. Cardiotoxicity associated with 5-FU/capecitabine and tyrosine kinase inhibitors are beyond the scope of this review.

Similar to anthracyclines, cardiotoxicity of radiation therapy is dose dependent [10]. Radiation and anthracyclines also have additive cardiotoxicity [11]. In HL, the cumulative incidence of cardiovascular disease 20 years after HL treatment is as high as 20% in patients who have received an anthracycline and mediastinal radiation [12]. In one study, the relative risk of death from myocardial was more than twofold compared with the general population (SMR = 2.5) [13].



In a study of breast cancer survivors, all-cause mortality rate was greater compared with women without breast cancer (HR: 1.8). Cardiovascular death rate in this study was also greater among longer-term survivors compared to control group after 7 years of follow-up [14].

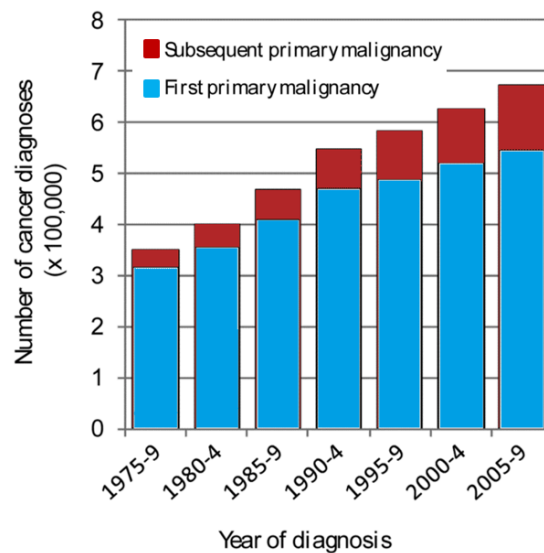
It is important to note that pre-existing cardiovascular risk factors, such as hypertension, diabetes, and dyslipidemia can increase the risk of late cardiovascular toxicities associated with cancer treatment [15]; careful management of these comorbid conditions during cancer therapy may therefore mitigate this risk.

Recognizing the clinical impact of late cardiac toxicities, the American Society of Clinical Oncology (ASCO) has developed an evidence-based practice guideline for prevention, assessment, and monitoring of cardiac dysfunction in survivors of adult cancers [16].

In summary, cardiovascular mortality and morbidity in survivors of specific cancers are common and potentially preventable. Conventional risk prediction models may not adequately assess the cardiovascular risk. Clinician's knowledge of patient's cancer treatment and pertinent guidelines are key to mitigate this risk.

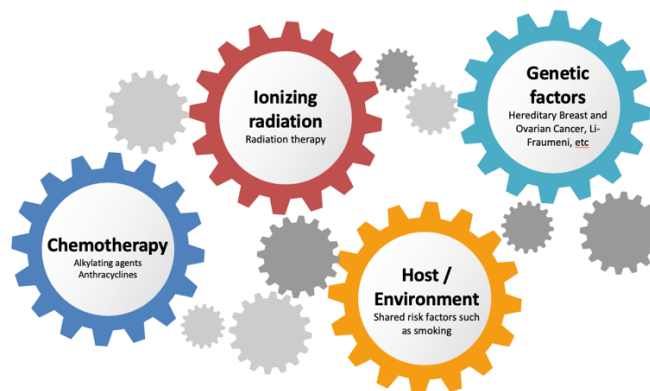
Subsequent primary cancers:

One in every 5 cancers is a subsequent primary malignancy. Data shows the percentage of subsequent cancer to have increased from 9% in 1975-1979 to 19% in 2005-2009 period [17]. This increase is due to a combination of more aggressive therapies and longer survival of individuals after their first cancer diagnosis.



Occurrence of first and subsequent primary malignancies among adults during 1975-2009 in nine SEER registries.

Cancer survivors are at higher risk of developing a new primary malignancy than the general population. This increased risk is likely due to several factors including: late treatment effects (alkylating agents, radiation); genetic predispositions (e.g. Li-Fraumeni syndrome); and shared host/environment factors (e.g. smoking is a risk factor for several cancers).



In 2006, the NCI published a report on new malignancies in cancer survivors. This report utilized data from NCI's SEER Program cancer registries to evaluate the risk of subsequent malignancy among more than 2 million cancer survivors for the period 1973

to 2000, and included data on more than 50 adult and 18 childhood cancer sites. Key findings from this report include [18]:

- Cancer survivors have a 14% higher risk of developing a subsequent cancer
- Tobacco/alcohol-related cancer sites accounted for more than 35% of the total excess subsequent cancers.
- Children and young adults seemed especially prone to the carcinogenic effects of radiotherapy and chemotherapy.

A subsequent study on survivors of the 10 most common cancer in the US – using SEER database 1992-2008 - showed that nearly 1 in 12 patients (8.1%) developed a second malignancy [19]. The most common second primary was lung cancer (18%). An alarming statistic is that >50% of patients with 2 incident cancers died of their second malignancy.

SEER data also shows that the survivors of head and neck cancers develop second primary lung cancer (SPLC) at standardized incidence rates which greatly exceeds the rate observed in the control arm of the National Lung Screening Trial [20]. Over half (57%) of patients with SPLC died of the disease. This study underscores the importance of screening for subsequent primary cancers as well as preventive measures such as smoking cessation.

Management of patients with genetic cancer predisposition is commonly done by oncology providers based on existing surveillance guidelines and is beyond the scope of this review.

In summary, new primary malignancies occur with higher rate in cancer survivors. Although specific guidelines are lacking, provider's awareness of the risk, preventive strategies, aggressive lifestyle modification, and screening are critical measures to improve the outcomes.

Other physical effects of cancer treatment:

Symptom burden in cancer survivors is substantial. In a national cross-sectional survey of cancer survivors by the American Cancer Society, 38.2% of responders reported an unmet need in the physical domain [21].

In another survey study of more than 2,800 patients with breast, colorectal, prostate, or lung cancer, 27.2% of patients who had completed primary cancer therapy reported three or more moderate to severe symptoms [22]. Fatigue (26.7%), disturbed sleep (22.1%), and pain (17.7%) were the most common symptoms reported out of 13 choices. It should be noted that chemotherapy induced cognitive impairment was not included in this study. "Chemo-brain" is a clinically under-recognized yet significant complication of cancer treatment [23]. Longitudinal neuropsychological assessment research studies in cancer patients indicate that up to 35% of patients experience chemotherapy induced cognitive impairment months or years following completion of treatments for cancer [24].

Oncologic surgery can also contribute to the symptom burden. Examples of surgery related physical effects/symptoms are lymphedema, chronic pain, functional limitations, sexual dysfunction, infertility, ostomy, and infection.

Uncontrolled symptoms can impair patient's quality of life, adherence to treatment/surveillance, and ability to return to work.

Screening for late effects should be part of the routine care of cancer survivors. The NCCN's Guideline for Survivorship Care includes a survey that can be administered by the patient. This questionnaire is linked to specific algorithms for further assessment and management of patient's symptoms. ASCO has also developed/adapted practice guidelines for assessment, prevention and management of several late/long-term effects of cancer treatment including fatigue, peripheral neuropathy and anxiety/depressive symptoms.

Health promotion and physical well-being:

Cancer survivors are often highly motivated to seek information about food choices, physical activity, and dietary supplements, and other means to improve their treatment outcomes, quality of life, and overall survival. Health promotion efforts in survivors, similar to every other individual, should include weight management, healthy diet, increased physical activity, smoking cessation, and reduced alcohol intake. The ACS report on nutrition and physical activity is a great resource for clinicians to review the evidence-based recommendations for cancer survivors [25]. NCCN guidelines for survivorship, and for smoking cessation also contain practical information on health promotion.

Psychological well-being in cancer survivors:

NCCN defines distress as "a multifactorial unpleasant experience of a psychological (i.e., cognitive, behavioral, emotional), social, spiritual, and/or physical nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment". Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis. Prevalence of distress among cancer patients ranges between 29.6% of gynecologic malignancies to 43.4% in lung cancer [26]. Anxiety (17.9%) and depression (11.6%) are also common among cancer survivors and their spouses [27]. In a pooled analysis of 5 studies, the prevalence of anxiety was 28.0% in the pooled sample of 691 cancer survivors and 40.1% in 539 spouses [27].

Some of the risk factors for psychosocial distress in cancer patients include recurrence, advanced disease, pain, disability, adolescence/young adult age, infertility, low/lack of social support, female gender, tobacco dependence, financial distress, and history of a mental health diagnosis.

Psychosocial factors can affect the quality of life. These factors include [28]:

- Fear of relapse
- Body image consciousness, awareness of “being different”
- Concerns about sexuality and fertility
- Stigmatization and discrimination
- Employment, insurance
- Meeting family’s expectations
- Reassimilating with their peer groups

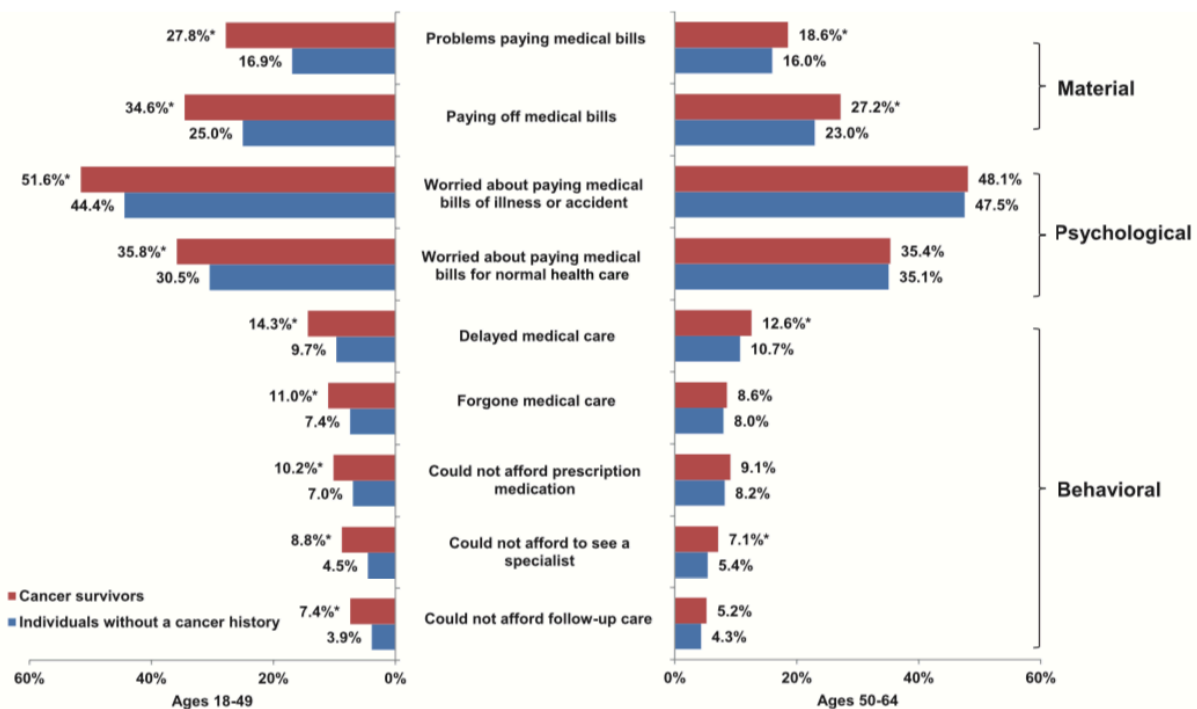
Failure to identify and treat anxiety and depression in the context of cancer, increases the risk for poor quality of life, and potentially increased disease-related morbidity and mortality. In one study, survivors with depressive symptoms had twofold risk for all-cause mortality, even after adjustment for major clinical predictors [29]. ASCO has adapted the Pan-Canadian guidelines for screening, assessment, and care of anxiety and depressive symptoms [30]. Based on these guidelines, it is recommended that all patients with cancer and cancer survivors be evaluated for symptoms of depression and anxiety at periodic times across the trajectory of care. Assessment should be performed using validated measures. PHQ-2/PHQ9 (for depression) and GAD-7 (for anxiety) questionnaires are examples of such validated tools. NCCN survivorship guideline also contains questionnaires and algorithm for screening, assessment and management of psychosocial needs, including and beyond depression and anxiety.

Economic considerations in cancer survivorship:

Cancer treatment can have significant socioeconomic consequences for the patients [31]. Financial toxicity of cancer care has become a focus of attention in recent years. Impact of financial hardship can be material (accruing debt), psychologic (worrying about cost of care), and/or behavioral (not seeking care). Cancer history is associated with lower asset ownership, more debt, and lower net worth, especially in survivors age 45-54 years [32]. A study using the 2008 to 2010 Medical Expenditure Panel Survey, estimated the average annual excess economic burden of cancer survivorship at >\$16,000 within the first year, and >\$4,000 annually afterwards [33].

In a national cross-sectional survey of cancer survivors by the American Cancer Society, 20% of responders reported an unmet financial need [21]. One study found that one third of working age survivors went in to debt and 3% filed for bankruptcy [34].

A study in Washington State showed that cancer patients were 2.65 times more likely to go bankrupt than people without cancer. Younger cancer patients had 2–5 times higher rates of bankruptcy than cancer patients ≥ 65 years old [35].



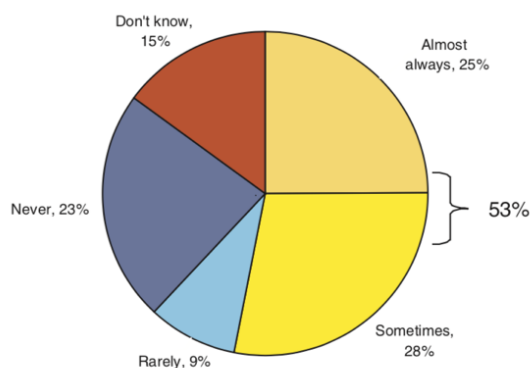
Adjusted proportions of cancer survivors and those without a cancer history reporting material, psychological, and behavioral medical financial hardship (stratified by age groups of 18-49 years and 50-64 years). An asterisk indicates a P value <.05. [36]

From Cancer Patient to Cancer Survivor: Lost in Transition

Physical, psychosocial and socioeconomic effects of cancer diagnosis and treatment have been recognized for decades, yet survivorship care has remained fragmented and inadequate. The growing population of cancer survivors, and their unique needs, prompted a study by the Institute of Medicine in 2006 - From Cancer Patient to Cancer Survivor: Lost in Transition [37]. The IOM report defines the essential components of survivorship care as follows:

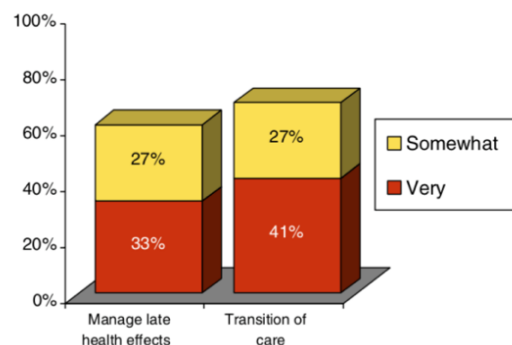
- **Prevention** of recurrent and new cancers, and of other late effects
- **Surveillance** for cancer spread, recurrence, or second cancers; assessment of medical and psychosocial late effects
- **Intervention** for consequences of cancer and its treatment
- **Coordination** between specialists and primary care providers to ensure that all of the survivor's health needs are met

Communication between cancer care team and the primary care physician is critical in survivorship care. A survey by the BlueCross of California of primary care physicians illustrates this point [38]. Among respondents, only 25 percent said that they “almost always” received a detailed end-of-treatment summary from the oncologist treating their patients. The PCPs were also asked two additional questions: “How prepared are you to monitor and manage your patients’ late health effects that may arise as a result of the therapeutic exposures used during cancer treatment?” and “How prepared are you to handle transition-of-care issues for your patients after discharge from cancer treatment, including communication with oncology providers?” Only 33% of the PCPs felt “very prepared” for managing the late health effects, and 41% felt “very prepared” about the transition care. Notably, there was an increased perceived ability to manage the late health effects and the handling of transition issues when providers had received end-of-treatment summaries from oncologists.



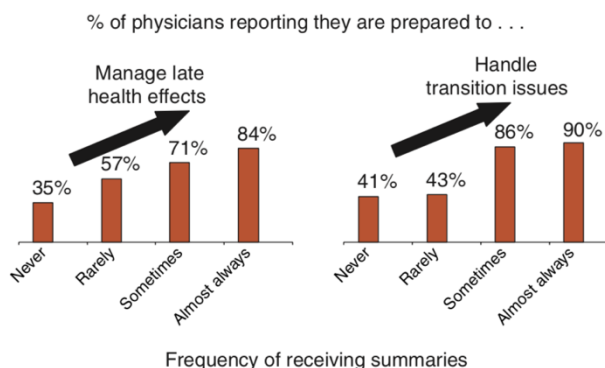
Primary care physicians receiving end-of-treatment summaries from oncologists.

Perception of Preparedness



Primary care providers' confidence in managing cancer patients' late health effects.

Relationship between confidence of the primary care physicians in managing cancer patients' late effects and receipt of an end-of-treatment summary.



IOM Report
From Cancer Patient to Cancer Survivor: Lost in Transition
RECOMMENDATIONS ^[37]

Recommendation 1: Health care providers, patient advocates, and other stakeholders should work to raise awareness of the needs of cancer survivors, establish cancer survivorship as a distinct phase of cancer care, and act to ensure the delivery of appropriate survivorship care.

Recommendation 2: Patients completing primary treatment should be provided with a comprehensive care summary and follow-up plan that is clearly and effectively explained. This “Survivorship Care Plan” should be written by the principal provider(s) who coordinated oncology treatment. This service should be reimbursed by third party payors of health care.

Recommendation 3: Health care providers should use systematically developed evidence-based clinical practice guidelines, assessment tools, and screening instruments to help identify and manage late effects of cancer and its treatment. Existing guidelines should be refined and new evidence-based guidelines should be developed through public- and private-sector efforts.

Recommendation 4: Quality of survivorship care measures should be developed through public/private partnerships and quality assurance programs implemented by health systems to monitor and improve the care that all survivors receive.

Recommendation 5: The Centers for Medicare and Medicaid Services, National Cancer Institute, Agency for Healthcare Research and Quality, the Department of Veterans Affairs, and other qualified organizations should support demonstration programs to test models of coordinated, interdisciplinary survivorship care in diverse communities and across systems of care.

Recommendation 6: Congress should support Centers for Disease Control and Prevention, other collaborating institutions, and the states in developing comprehensive cancer control plans that include consideration of survivorship care, and promoting the implementation, evaluation, and refinement of existing state cancer control plans.

Recommendation 7: The National Cancer Institute, professional associations, and voluntary organizations should expand and coordinate their efforts to provide educational opportunities to health care providers to equip them to address the health care and quality of life issues facing cancer survivors.

Recommendation 8: Employers, legal advocates, health care providers, sponsors of support services, and government agencies should act to eliminate discrimination and minimize adverse effects of cancer on employment, while supporting cancer survivors with short-term and long-term limitations in ability to work.

Recommendation 9: Federal and state policy makers should act to ensure that all cancer survivors have access to adequate and affordable health insurance. Insurers and payors of health care should recognize survivorship care as an essential part of cancer care and design benefits, payment policies, and reimbursement mechanisms to facilitate coverage for evidence-based aspects of care.

Recommendation 10: The National Cancer Institute, Centers for Disease Control and Prevention, Agency for Healthcare Research and Quality, Centers for Medicare and Medicaid Services, Department of Veterans Affairs, private voluntary organizations such as the American Cancer Society, and private health insurers and plans should increase their support of survivorship research and expand mechanisms for its conduct. New research initiatives focused on cancer patient follow-up are urgently needed to guide effective survivorship care.

Survivorship Care Plan [37,39]

Upon discharge from cancer treatment, including treatment of recurrences, every patient should be given a record of all care received and important disease characteristics. This should include, at a minimum:

1. Diagnostic tests performed and results.
2. Tumor characteristics (e.g., site(s), stage and grade, hormone receptor status, marker information).
3. Dates of treatment initiation and completion.
4. Surgery, chemotherapy, radiotherapy, transplant, hormonal therapy, or gene or other therapies provided, including agents used, treatment regimen, total dosage, identifying number and title of clinical trials (if any), indicators of treatment response, and toxicities experienced during treatment.
5. Psychosocial, nutritional, and other supportive services provided.
6. Full contact information on treating institutions and key individual providers.
7. Identification of a key point of contact and coordinator of continuing care.

Upon discharge from cancer treatment, every patient and his/her primary health care provider should receive a written follow-up care plan incorporating available evidence-based standards of care. This should include, at a minimum:

1. The likely course of recovery from treatment toxicities, as well as the need for ongoing health maintenance/adjuvant therapy.
2. A description of recommended cancer screening and other periodic testing and examinations, and the schedule on which they should be performed (and who should provide them).
3. Information on possible late and long-term effects of treatment and symptoms of such effects.
4. Information on possible signs of recurrence and second tumors.
5. Information on the possible effects of cancer on marital/partner relationship, sexual functioning, work, and parenting, and the potential future need for psychosocial support.
6. Information on the potential insurance, employment, and financial consequences of cancer and, as necessary, referral to counseling, legal aid, and financial assistance.
7. Specific recommendations for healthy behaviors (e.g., diet, exercise, healthy weight, sunscreen use, immunizations, smoking cessation, osteoporosis prevention). When appropriate, recommendations that first-degree relatives be informed about their increased risk and the need for cancer screening (e.g., breast cancer, colorectal cancer, prostate cancer).
8. As appropriate, information on genetic counseling and testing to identify high-risk individuals who could benefit from more comprehensive cancer surveillance, chemoprevention, or risk-reducing surgery.
9. As appropriate, information on known effective chemoprevention strategies for secondary prevention (e.g., tamoxifen in women at high risk for breast cancer; aspirin for colorectal cancer prevention).
10. Referrals to specific follow-up care providers (e.g., rehabilitation, fertility, psychology), support groups, and/or the patient's primary care provider.
11. A listing of cancer-related resources and information

The IOM report recommended that patients completing their primary treatment for cancer, as well as their primary care providers, should be provided with a summary of their treatment and a comprehensive plan for follow-up. Such a plan would inform patients and their providers of the long-term effects of cancer and its treatment, identify psychosocial support resources in their communities, and provide guidance on follow-up care, prevention, and health maintenance.

The IOM report identified key elements that should be included in the Survivorship Care Plan:

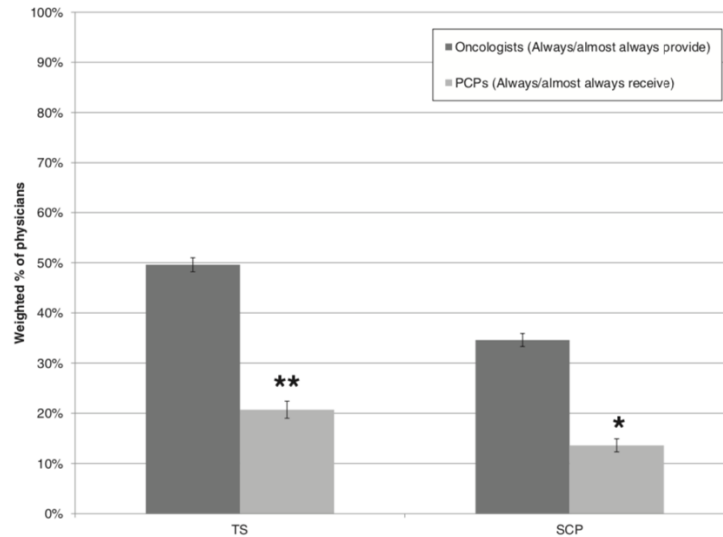
- Specific tissue diagnosis and stage
- Initial treatment plan and dates of treatment
- Toxicities during treatment
- Expected short- and long-term effects of therapy
- Late toxicity monitoring needed
- Surveillance for recurrence or second cancer
- Who will take responsibility for survivorship care
- Psychosocial and vocational needs
- Recommended preventive behaviors/interventions

As a follow-up to the *Lost in Transition* report, IOM held a workshop on "*Implementing Cancer Survivorship Care Planning*" to determine the next steps to implementing cancer survivorship care planning [38].

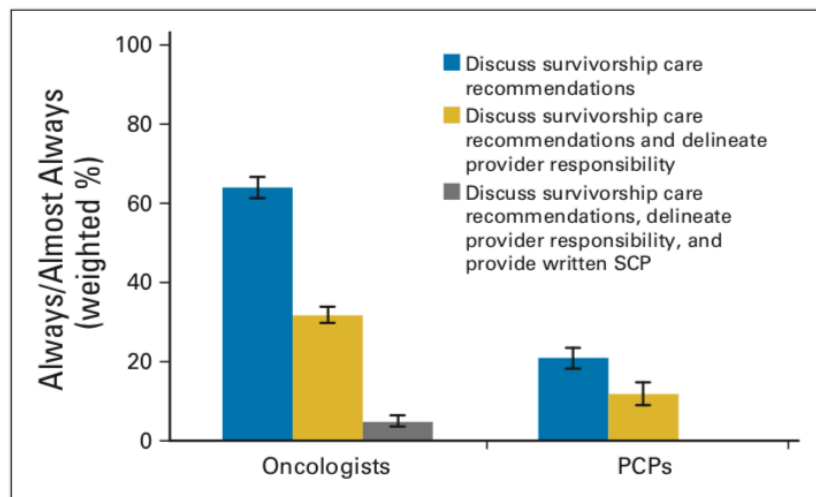
In 2011, LIVESTRONG Foundation invited national cancer survivorship experts to participate in the Essential Elements of Survivorship Care Meeting. The goal of the meeting was to build consensus among key stakeholders on the essential elements of survivorship care that any effective cancer survivorship program must provide to post-treatment cancer survivors [40].

Survivorship care plan (SCP) was also recognized a quality measure. In 2012, the Commission on Cancer (CoC) introduced a "phase in" standard to address SCPs. Under standard 3.3, "the cancer committee is tasked to develop and implement a process to disseminate a comprehensive care summary and follow-up plan to patients with cancer who are completing cancer treatment. The process is monitored, evaluated, and presented at least annually to the cancer committee and documented in minutes" [41]. In 2016, CoC included a schedule for implementation of SCPs based on which cancer programs should provide SCPs to at least 75% of eligible patients by the end of 2018 [42].

Unfortunately, adoption and implementation of care plans and care planning processes have generally remained low [43-45].



Physician-reported provision and receipt of treatment summaries and survivorship care plans. Survivorship care plans are defined as a treatment summary plus follow-up care plan. *P = .001 and **P < .001. [44].



Oncologists and primary care physicians (PCPs) reporting discussion of survivorship care and provision of survivorship care plans (SCPs) to survivors [45].

Conclusion:

Cancer survivors constitute a rapidly expanding part of the US population. Considering the long-term and late effects of cancer/cancer treatment, care of cancer survivors poses a public health challenge. Existing and emerging data suggest significant gaps in knowledge, research, and care of cancer survivors. Despite efforts by professional societies, patient advocacy groups, and regulatory/quality organizations, care of cancer survivors remains fragmented and inadequate. More than a decade has passed since the IOM seminal report: *Lost in Translation*; while significant strides have been made in most domains, progress in other areas have been slow and incremental.

It is important to remember that care plan is not just a communication tool between the oncologist and primary care provider; it is also to empower the patient as part of the care team. Raising awareness of patients and providers, patient navigation, incorporating formal training on survivorship care in pertinent specialties, leveraging EMR to reduce the documentation burden and produce tailored care plans, and finally, institutional commitment to develop “programs” rather than focusing on “components” are instrumental in integration of survivorship care in to routine clinical practice.

References:

1. Aziz NM, Rowland JH. Trends and advances in cancer survivorship research: challenge and opportunity. *Semin Radiat Oncol*. 2003 Jul;13(3):248-66. Review. PubMed PMID: 12903014.
2. Siegel RL, Miller KD, Jemal A. Cancer statistics, 2019. *CA Cancer J Clin*. 2019 Jan;69(1):7-34. PubMed PMID: 30620402.
3. Miller KD, Nogueira L, et al. Cancer treatment and survivorship statistics, 2019. *CA Cancer J Clin*. 2019 Jun 11. doi: 10.3322/caac.21565. [Epub ahead of print] PubMed PMID: 31184787
4. Bluethmann SM, Mariotto AB, Rowland JH. Anticipating the "Silver Tsunami": Prevalence Trajectories and Comorbidity Burden among Older Cancer Survivors in the United States. *Cancer Epidemiol Biomarkers Prev*. 2016 Jul;25(7):1029-36. PubMed PMID: 27371756.
5. Shapiro CL. Cancer Survivorship. *N Engl J Med*. 2018 Dec 20;379(25):2438-2450. PubMed PMID: 30575480.
6. Yancik R. Cancer burden in the aged: an epidemiologic and demographic overview. *Cancer*. 1997 Oct 1;80(7):1273-83. Review. PubMed PMID: 9317180.
7. Hudson MM, Poquette CA, et al. Increased mortality after successful treatment for Hodgkin's disease. *J Clin Oncol*. 1998 Nov;16(11):3592-600. PubMed PMID: 9817280.
8. Matasar MJ, Ford JS, et al. Late morbidity and mortality in patients with Hodgkin's lymphoma treated during adulthood. *J Natl Cancer Inst*. 2015 Feb 24;107(4). PubMed PMID: 25717170.
9. Ewer MS, Ewer SM. Cardiotoxicity of anticancer treatments. *Nat Rev Cardiol*. 2015 Sep;12(9): 547-58. Erratum in: *Nat Rev Cardiol*. 2015 Nov;12(11):620. PubMed PMID: 25962976.
10. van Nimwegen FA, Schaapveld M, et al. Radiation Dose-Response Relationship for Risk of Coronary Heart Disease in Survivors of Hodgkin Lymphoma. *J Clin Oncol*. 2016 Jan 20;34(3):235-43. PubMed PMID: 26573075.
11. van Nimwegen FA, Ntents G, et al. Risk of heart failure in survivors of Hodgkin lymphoma: effects of cardiac exposure to radiation and anthracyclines. *Blood*. 2017 Apr 20;129(16):2257-2265. PubMed PMID: 28143884.
12. van Nimwegen FA, Schaapveld M, et al. Cardiovascular disease after Hodgkin lymphoma treatment: 40-year disease risk. *JAMA Intern Med*. 2015 Jun;175(6):1007-17. PubMed PMID: 25915855.
13. Swerdlow AJ, Higgins CD, et al. Myocardial infarction mortality risk after treatment for Hodgkin disease: a collaborative British cohort study. *J Natl Cancer Inst*. 2007 Feb 7;99(3):206-14. PubMed PMID: 17284715.
14. Bradshaw PT, Stevens J, et al. Cardiovascular Disease Mortality Among Breast Cancer Survivors. *Epidemiology*. 2016 Jan;27(1):6-13. PubMed PMID: 26414938.
15. Salz T, Zabor EC, et al. Preexisting Cardiovascular Risk and Subsequent Heart Failure Among Non-Hodgkin Lymphoma Survivors. *J Clin Oncol*. 2017 Dec 1;35(34):3837-3843. PubMed PMID: 28922087.
16. Armenian SH, Lacchetti C, et al. Prevention and Monitoring of Cardiac Dysfunction in Survivors of Adult Cancers: American Society of Clinical Oncology Clinical Practice Guideline. *J Clin Oncol*. 2017 Mar 10;35(8):893-911. PubMed PMID: 27918725.
17. Morton LM, Onel K, et al. The rising incidence of second cancers: patterns of occurrence and identification of risk factors for children and adults. *Am Soc Clin Oncol Educ Book*. 2014:e57-67. PubMed PMID: 24857148.
18. Curtis RE, Freedman DM, Ron E, Ries LAG, Hacker DG, Edwards BK, Tucker MA, Fraumeni JF Jr. (eds). *New Malignancies Among Cancer Survivors: SEER Cancer Registries, 1973-2000*. National Cancer Institute. NIH Publ. No. 05-5302. Bethesda, MD, 2006.
19. Donin N, Filson C, et al. Risk of second primary malignancies among cancer survivors in the United States, 1992 through 2008. *Cancer*. 2016 Oct;122(19):3075-86. PubMed PMID: 27377470.
20. Donin NM, Kwan L, et al. Second primary lung cancer in United States Cancer Survivors, 1992-2008. *Cancer Causes Control*. 2019 May;30(5):465-475. PubMed PMID: 30900065.
21. Burg MA, Adorno G, et al. Current unmet needs of cancer survivors: analysis of open-ended responses to the American Cancer Society Study of Cancer Survivors II. *Cancer*. 2015 Feb 15;121(4):623-30. PubMed PMID: 25581252.

22. Cleeland CS, Zhao F, et al. The symptom burden of cancer: Evidence for a core set of cancer-related and treatment-related symptoms from the Eastern Cooperative Oncology Group Symptom Outcomes and Practice Patterns study. *Cancer*. 2013 Dec 15;119(24):4333-40. PubMed PMID: 24114037.
23. Vitali M, Ripamonti CI, et al. Cognitive impairment and chemotherapy: a brief overview. *Crit Rev Oncol Hematol*. 2017 Oct;118:7-14. PubMed PMID: 28917271.
24. Janelins MC, Kesler SR, Ahles TA, Morrow GR. Prevalence, mechanisms, and management of cancer-related cognitive impairment. *Int Rev Psychiatry*. 2014 Feb;26(1):102-13. PubMed PMID: 24716504.
25. Rock CL, Doyle C, et al. Nutrition and physical activity guidelines for cancer survivors. *CA Cancer J Clin*. 2012 Jul-Aug;62(4):243-74. PubMed PMID: 22539238.
26. Zabora J, BrintzenhofeSzoc K, et al. The prevalence of psychological distress by cancer site. *Psychooncology*. 2001 Jan-Feb;10(1):19-28. PubMed PMID: 11180574.
27. Mitchell AJ, Ferguson DW, et al. Depression and anxiety in long-term cancer survivors compared with spouses and healthy controls: a systematic review and meta-analysis. *Lancet Oncol*. 2013 Jul;14(8):721-32. PubMed PMID: 23759376.
28. Surbone A, Baider L, et al. Psychosocial care for patients and their families is integral to supportive care in cancer: MASCC position statement. *Support Care Cancer*. 2010 Feb;18(2):255-63. PubMed PMID: 19609571.
29. Mols F, Husson O, et al. Depressive symptoms are a risk factor for all-cause mortality: results from a prospective population-based study among 3,080 cancer survivors from the PROFILES registry. *J Cancer Surviv*. 2013 Sep;7(3):484-92. PubMed PMID: 23677523.
30. Andersen BL, DeRubeis RJ, et al. Screening, assessment, and care of anxiety and depressive symptoms in adults with cancer: an American Society of Clinical Oncology guideline adaptation. *J Clin Oncol*. 2014 May 20;32(15):1605-19. PubMed PMID: 24733793.
31. Yabroff KR, Zhao J, et al. Medical Financial Hardship among Cancer Survivors in the United States: What Do We Know? What Do We Need to Know? *Cancer Epidemiol Biomarkers Prev*. 2018 Dec;27(12):1389-1397. PubMed PMID: 30429132.
32. Doroudi M, Coughlan D, et al. Is Cancer History Associated With Assets, Debt, and Net Worth in the United States? *JNCI Cancer Spectr*. 2018 Apr 20;2(2):pky004. PubMed PMID: 31360843.
33. Guy GP Jr, Ekwueme DU, et al. Economic burden of cancer survivorship among adults in the United States. *J Clin Oncol*. 2013 Oct 20;31(30):3749-57. PubMed PMID: 24043731.
34. Banegas MP, Guy GP Jr, et al. For Working-Age Cancer Survivors, Medical Debt And Bankruptcy Create Financial Hardships. *Health Aff (Millwood)*. 2016 Jan;35(1):54-61. PubMed PMID: 26733701.
35. Ramsey S, Blough D, et al. Washington State cancer patients found to be at greater risk for bankruptcy than people without a cancer diagnosis. *Health Aff (Millwood)*. 2013 Jun;32(6):1143-52. PubMed PMID: 23676531.
36. Zheng Z, Jemal A, et al. Medical financial hardship among cancer survivors in the United States. *Cancer*. 2019 May 15;125(10):1737-1747. PubMed PMID: 30663039.
37. National Research Council 2006. From Cancer Patient to Cancer Survivor: Lost in Transition. Washington, DC: The National Academies Press. <https://doi.org/10.17226/11468>
38. Institute of Medicine 2007. Implementing Cancer Survivorship Care Planning: Workshop Summary. Washington, DC: The National Academies Press. <https://doi.org/10.17226/11739>
39. President's Cancer Panel. 2004. Living Beyond Cancer: Finding a New Balance. Bethesda, MD: National Cancer Institute.
40. Rechis, R, et al. The essential elements of survivorship care: A LIVESTRONG brief. 2011. Available online at: <https://www.livestrong.org/sites/default/files/what-we-do/reports/EssentialElementsBrief.pdf>
41. Cancer Program Standards: Ensuring Patient-Centered Care (2012 Edition). Commission on Cancer. Available online at: <https://www.facs.org/~media/files/quality%20programs/cancer/coc/programstandards2012.ashx>
42. Cancer Program Standards: Ensuring Patient-Centered Care (2016 Edition). Commission on Cancer. Available online at: <https://www.facs.org/quality-programs/cancer/coc/standards>.

43. Tevaarwerk AJ, Sesto ME. Continued Challenges to the Adoption and Implementation of Survivorship Care Plans. *J Oncol Pract*. 2018 Oct;14(10):573-576. PubMed PMID: 30192692.
44. Forsythe LP, Parry C, et al. Use of survivorship care plans in the United States: associations with survivorship care. *J Natl Cancer Inst*. 2013 Oct 16;105(20):1579-87. PubMed PMID: 24096621.
45. Blanch-Hartigan D, Forsythe LP, et al. Provision and discussion of survivorship care plans among cancer survivors: results of a nationally representative survey of oncologists and primary care physicians. *J Clin Oncol*. 2014 May 20;32(15):1578-85. PubMed PMID: 24752057.

Online resources:

The NCCN guideline for cancer survivorship includes a comprehensive directory of online resources including practice guidelines, assessment tools, patient information resources, etc. Available online at:
https://www.nccn.org/professionals/physician_gls/pdf/survivorship.pdf