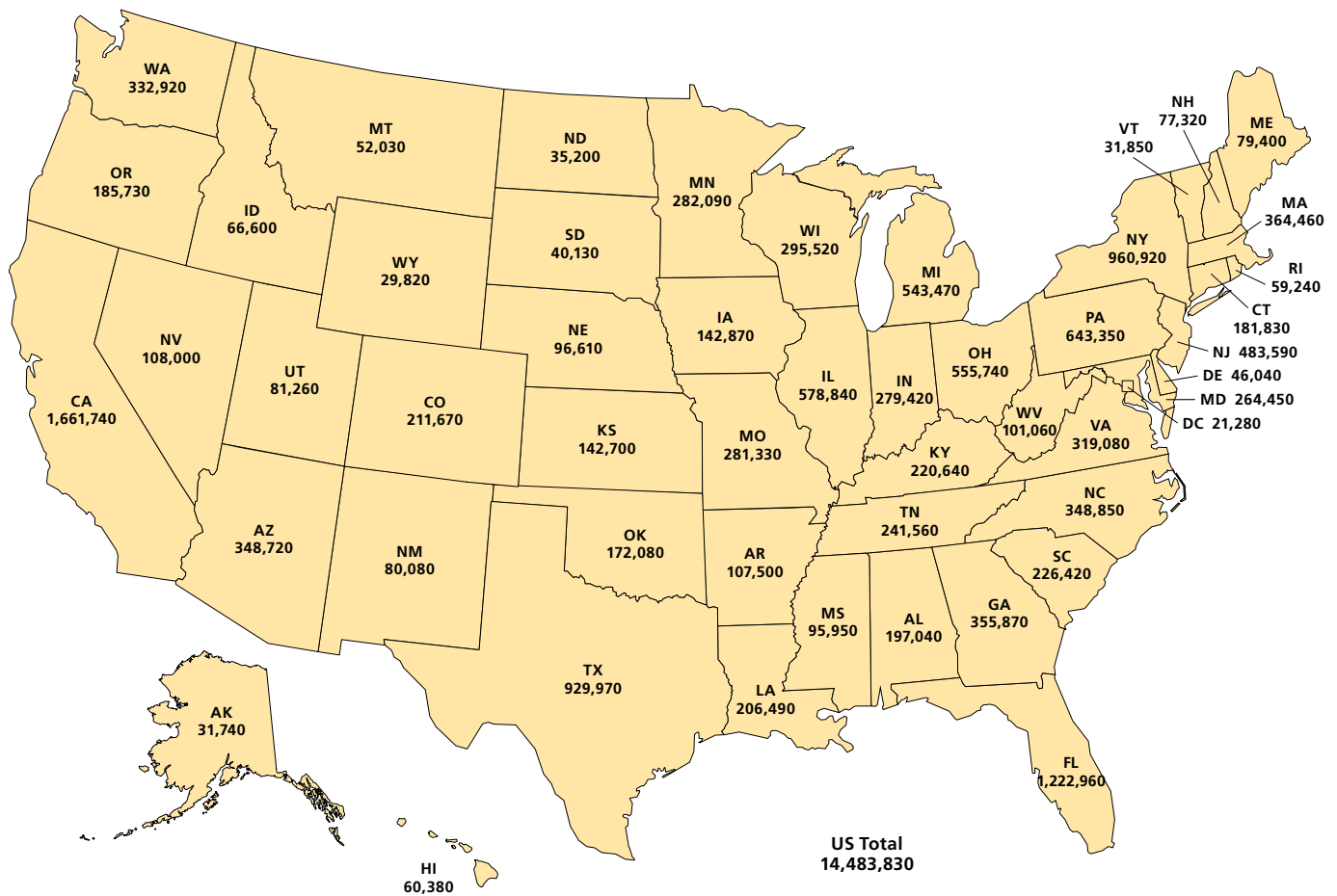


Cancer Treatment & Survivorship Facts & Figures

2014-2015

Estimated Numbers of Cancer Survivors by State as of January 1, 2014



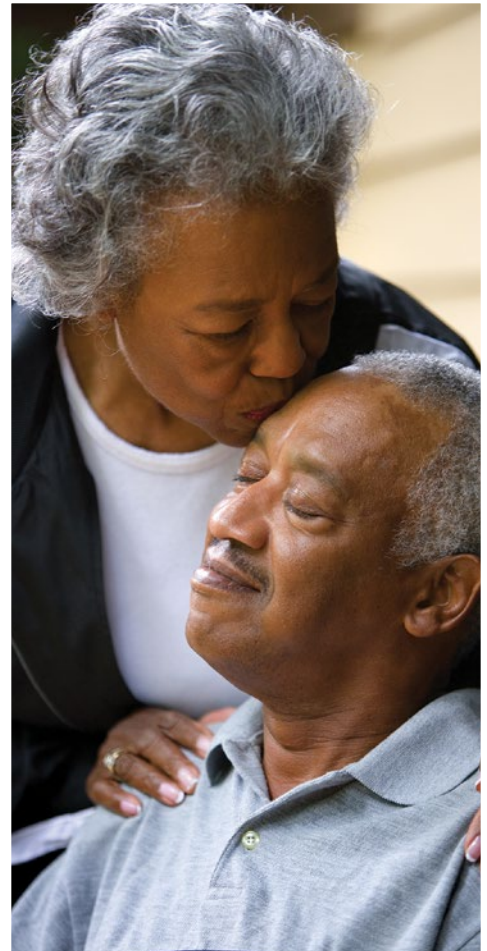
Note: State estimates do not sum to US total due to rounding.

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Introduction

Who Are Cancer Survivors?

A cancer survivor is any person who has been diagnosed with cancer, from the time of diagnosis through the balance of life. There are at least three distinct phases associated with cancer survival, including the time from diagnosis to the end of initial treatment, the transition from treatment to extended survival, and long-term survival.¹ In practice, however, the term “survivor” is often used to mean someone who has finished active treatment. Survivorship encompasses a range of cancer experiences and trajectories, including:

- Living cancer-free for the remainder of life
- Living cancer-free for many years but experiencing one or more serious, late complications of treatment
- Living cancer-free for many years, but dying after a late recurrence
- Living cancer-free after the first cancer is treated, but developing a second cancer
- Living with intermittent periods of active disease requiring treatment
- Living with cancer continuously without a disease-free period

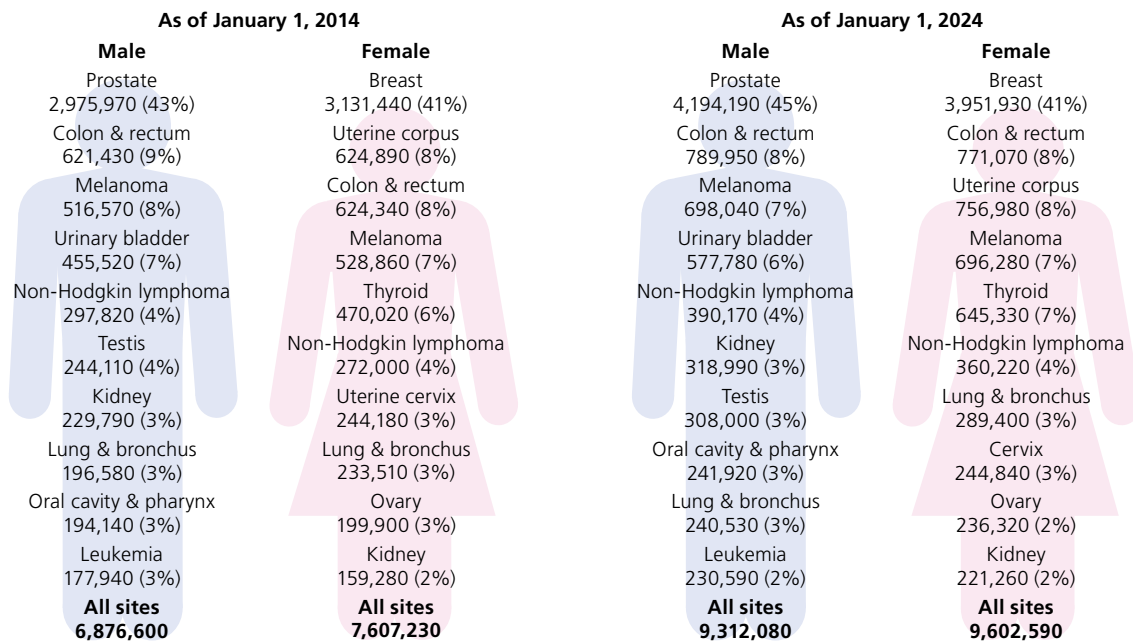
The goals of treatment are to “cure” the cancer if possible and/or prolong survival and provide the highest possible quality of life during and after treatment. A cancer is cured when all traces of the cancer have been removed from the patient’s body. Although it is usually not possible to know for sure if the cancer has been completely eradicated, for many patients diagnosed with cancer, the initial course of therapy is successful and the cancer never returns. However, even cancer-free survivors must cope with the long-term effects of treatment, as well as psychological concerns such as fear of recurrence. Cancer patients, caregivers, and survivors must have the information and support they need to play an active role in decisions that affect treatment and quality of life.

Throughout this document, the terms cancer patient and survivor are used interchangeably. It is also recognized that not all people with a cancer diagnosis identify with the term “cancer survivor.”

How Many Cancer Survivors Are Alive in the US?

Nearly 14.5 million children and adults with a history of cancer were alive on January 1, 2014, in the United States. This estimate does not include carcinoma in situ (non-invasive cancer) of any site except urinary bladder, nor does it include basal cell and squamous cell skin cancers. The 10 most common cancer sites represented among male and female survivors are shown in Figure 1. Prostate (43%), colon and rectum (9%), and melanoma (8%)

Figure 1. Estimated Numbers of US Cancer Survivors by Site



Source: Data Modeling Branch, Division of Cancer Control and Population Sciences, National Cancer Institute.

American Cancer Society, Surveillance and Health Services Research, 2014

are the three most common cancers among male cancer survivors and breast (41%), uterine corpus (8%), and colon and rectum (8%) are the most common among female survivors.

The majority of cancer survivors (64%) were diagnosed 5 or more years ago, and 15% were diagnosed 20 or more years ago (Table 1). Nearly half (46%) of cancer survivors are 70 years of age or older, while only 5% are younger than 40 years (Table 2).

How Many Cancer Survivors Are Expected to Be Alive in the US in 2024?

By January 1, 2024, it is estimated that the population of cancer survivors will increase to almost 19 million: 9.3 million males and 9.6 million females (Figure 1, page 1).



Table 1. Estimated Numbers of US Cancer Survivors as of January 1, 2014, by Sex and Time Since Diagnosis

Years since diagnosis	Male and Female			Male			Female		
	Number	Percent	Cumulative Percent	Number	Percent	Cumulative Percent	Number	Percent	Cumulative Percent
0 to <5 years	5,149,350	36%	36%	2,731,710	40%	40%	2,417,640	32%	32%
5 to <10 years	3,407,910	24%	59%	1,739,950	25%	65%	1,667,960	22%	54%
10 to <15 years	2,263,770	16%	75%	1,070,460	16%	81%	1,193,310	16%	69%
15 to <20 years	1,455,280	10%	85%	617,230	9%	90%	838,050	11%	80%
20 to <25 years	912,890	6%	91%	338,530	5%	94%	574,360	8%	88%
25 to <30 years	547,240	4%	95%	175,620	3%	97%	371,620	5%	93%
30+ years	747,400	5%	100%	203,100	3%	100%	544,300	7%	100%

Note: Percentages do not sum to 100% due to rounding.

Source: Data Modeling Branch, Division of Cancer Control and Population Sciences, National Cancer Institute.

Table 2. Estimated Number of US Cancer Survivors as of January 1, 2014, by Sex and Age at Prevalance

	Male and Female			Male			Female		
	Number	Percent	Cumulative Percent	Number	Percent	Cumulative Percent	Number	Percent	Cumulative Percent
All ages	14,483,830			6,876,600			7,607,230		
0-14	60,620	<1%	<1%	38,210	1%	1%	22,410	<1%	<1%
15-19	48,690	<1%	1%	24,950	<1%	1%	23,740	<1%	1%
20-29	185,500	1%	2%	77,470	1%	2%	108,030	1%	2%
30-39	399,720	3%	5%	140,770	2%	4%	258,950	3%	5%
40-49	985,470	7%	12%	347,780	5%	9%	637,690	8%	14%
50-59	2,388,540	16%	28%	971,660	14%	23%	1,416,880	19%	32%
60-69	3,811,640	26%	54%	1,858,250	27%	50%	1,953,390	26%	58%
70-79	3,762,310	26%	80%	2,026,380	29%	80%	1,735,930	23%	81%
80+	2,841,340	20%	100%	1,391,130	20%	100%	1,450,210	19%	100%

Note: Percentages do not sum to 100% due to rounding.

Source: Data Modeling Branch, Division of Cancer Control and Population Sciences, National Cancer Institute.

Selected Cancers

This section contains information about treatment, survival, and other related concerns for the most common cancer types. More information on the side effects of cancer treatment can be found beginning on page 22.

Breast (Female)

It is estimated that there were more than 3.1 million women living in the US with a history of invasive breast cancer as of January 1, 2014, and an additional 232,670 women will be newly diagnosed in 2014. The median age at the time of breast cancer diagnosis is 61 (Figure 2, page 4). About 20% of breast cancers occur among women younger than age 50 and 43% occur in those older than 65 years. The treatment and prognosis for breast cancer depend on the stage at diagnosis, the biological characteristics of the tumor, and the age and health of the patient. Overall, 61% of breast cancers are diagnosed at the localized stage (Figure 3, page 5). Mammography screening can often detect breast cancers at an early stage, when treatment may be more effective and there are more treatment options.

Treatment and survival

Surgical treatment for breast cancer usually involves breast-conserving surgery (BCS) (i.e., lumpectomy/partial mastectomy) or mastectomy (surgical removal of the breast). The decision about which option to choose is complex and often difficult for

women. Research shows that when BCS is appropriately used for localized or regional cancers and followed with radiation to the breast, long-term survival is the same as with mastectomy.² However, some patients require mastectomy for medical reasons, such as having large or multiple tumors or having contraindications to radiation therapy. Others elect mastectomy because of a reluctance to undergo radiation therapy after BCS, a fear of disease recurrence, or for other reasons.

Among women with early stage (I or II) breast cancer, 59% undergo BCS, 36% have a mastectomy, 4% receive radiation and/or chemotherapy, and about 1% do not receive any of these treatments (Figure 4, page 6). In contrast, among women with late-stage (III or IV) breast cancer, 13% undergo BCS, 59% have mastectomy, 16% receive radiation and/or chemotherapy, and 10% do not receive any of these treatments (Figure 4, page 6). Some who undergo mastectomy elect to have breast reconstruction, either with a saline or silicone implant, tissue taken from elsewhere in the body, or a combination thereof. Reported rates of breast reconstruction in the US vary widely; women who are younger, white, have private insurance, or have a higher education or income are more likely to undergo reconstruction.³

Axillary (underarm) lymph nodes are usually removed and evaluated during surgery to determine whether the tumor has spread beyond the breast. In women with early stage disease,

How Is Cancer Staged?

Staging describes the extent or spread of cancer at the time of diagnosis. Proper staging is essential in determining treatment options and assessing prognosis.

A number of different staging systems can be used. The TNM staging system assesses cancers in three ways: the size of the tumor (T) and/or whether it has grown to involve nearby areas, absence or presence of regional lymph node involvement (N), and absence or presence of distant metastases (M). Once the T, N, and M categories are determined, this information is combined to assign a stage of 0, I, II, III, or IV, with stage 0 referring to a non-invasive cancer that is limited to the cells in which it originated, stage I being early stage invasive cancer, and stage IV being the most advanced stage. The TNM staging system is commonly used in clinical settings.

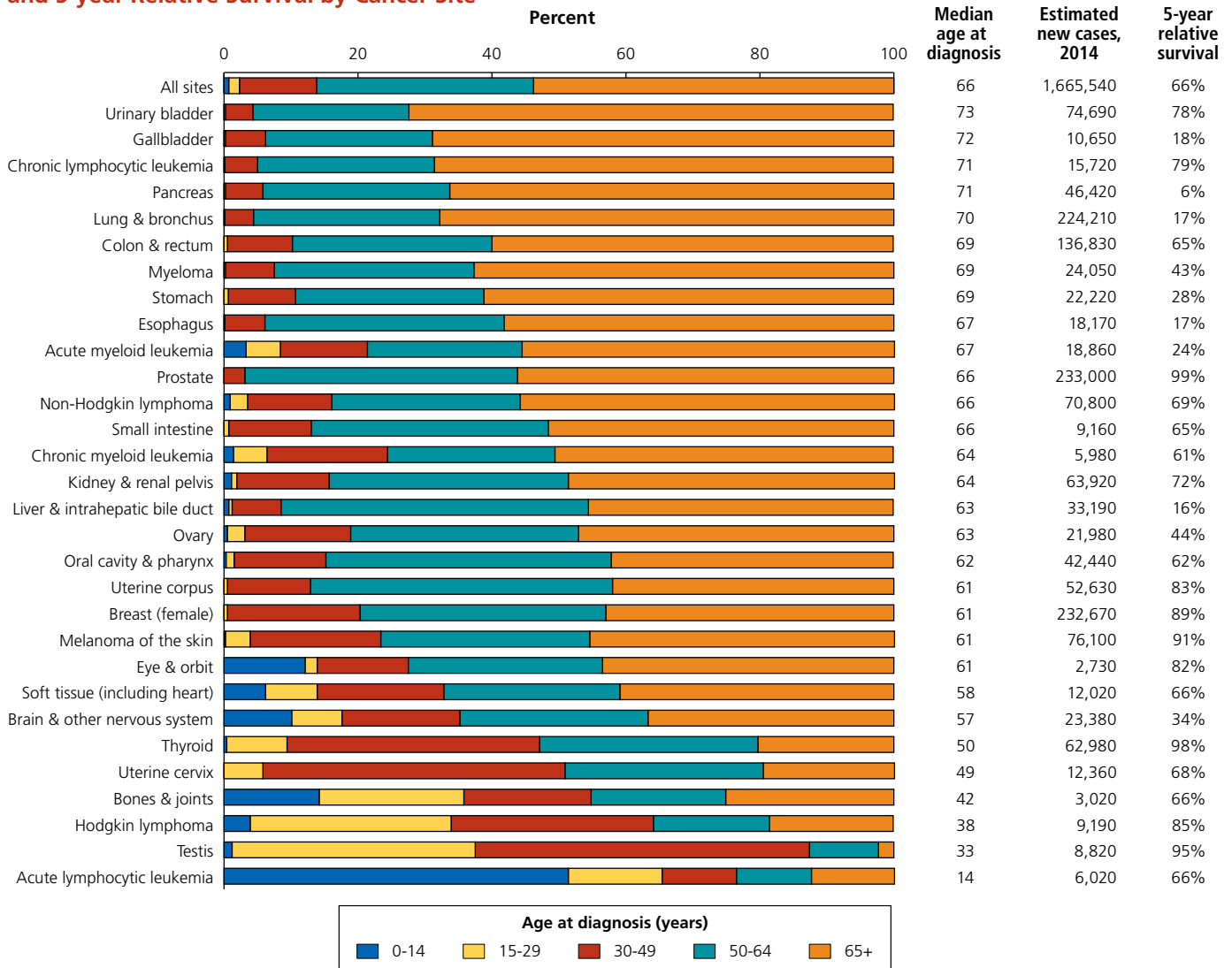
A second and less complex staging system, called Summary Stage, has historically been used by central cancer registries. Cancers are classified as in situ, local, regional, and distant. Cancer that is present only in the original layer of cells where it developed is classified as in situ. If cancer cells have penetrated

the original layer of tissue, the cancer is invasive and is categorized as local (confined to the organ of origin), regional (spread to nearby tissues or lymph nodes in the area of the organ of origin), or distant (spread to other organs or parts of the body).

Both the TNM and Summary Stage staging systems are used in this publication depending on the source of the cancer data (central registry [e.g., Surveillance, Epidemiology, and End Results (SEER) data] versus hospital registry [i.e., National Cancer Data Base (NCDB) data]). Although there are some exceptions, the TNM staging system generally corresponds to the Summary Stage system as follows:

- Stage 0 corresponds to in situ stage
- Stage I corresponds to local stage
- Stage II corresponds to either local or regional stage depending on lymph node involvement
- Stage III corresponds to regional stage
- Stage IV cancer corresponds to distant stage

Figure 2. Age Distribution of New Cases (%), Median Age at Diagnosis, Estimated Number of New Cases, and 5-year Relative Survival by Cancer Site



Note: Sites are ranked in order of median age at diagnosis from oldest to youngest.

Sources: Age distribution based on 2009-2010 data from NAACCR and excludes Arkansas, Nevada, and Ohio. Median age at diagnosis and 5-year relative survival are based on cases diagnosed during 2006-2010 and 2003-2009, respectively, from the 18 SEER registries and were previously published in the *SEER Cancer Statistics Review, 1975-2010*.²⁵ 2014 estimated cases from *Cancer Statistics, 2014*.²⁰⁶

American Cancer Society, Surveillance and Health Services Research, 2014

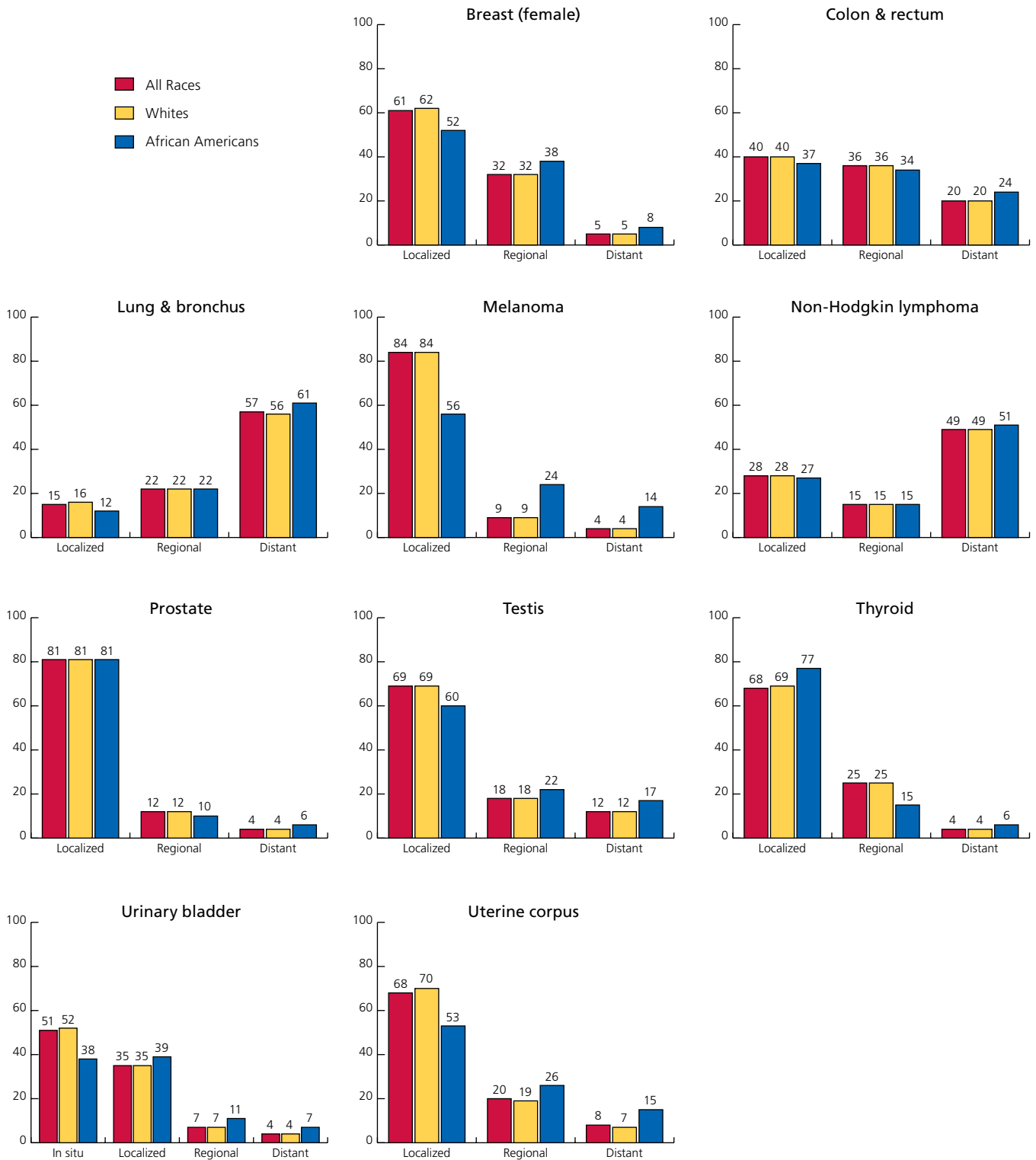
sentinel lymph node biopsy (SLNB) has a lower chance of long-term side effects and is as informative as a full axillary node dissection, in which many nodes are removed.⁴

Treatment may also involve radiation therapy, chemotherapy, hormone therapy (e.g., tamoxifen, aromatase inhibitors, ovarian ablation, or luteinizing hormone-releasing hormone [LHRH] analogs), or targeted therapy (drugs that work by attacking specific parts of cancer cells). Radiation is recommended for nearly all women undergoing BCS and is also indicated after a mastectomy in certain situations. Approximately 56% of breast cancer patients receive radiation therapy.

The benefit of chemotherapy is dependent on multiple factors, including the size of the tumor, the number of lymph nodes involved, the presence of hormone receptors (ER or PR), and the amount of human epidermal growth factor receptor 2 (HER2) protein made by the cancer cells.

Women with breast cancer that tests positive for hormone receptors are candidates for treatment with hormone therapy to reduce the likelihood of recurrence. For premenopausal women, the standard hormonal treatment after curative surgery is tamoxifen for 5 years. For those who are postmenopausal, hormonal treatment may include tamoxifen and/or an aromatase inhibitor (e.g., letrozole [Femara], anastrozole [Arimidex], or

Figure 3. Distribution (%) of Selected Cancers by Race and Stage at Diagnosis, 2003-2009

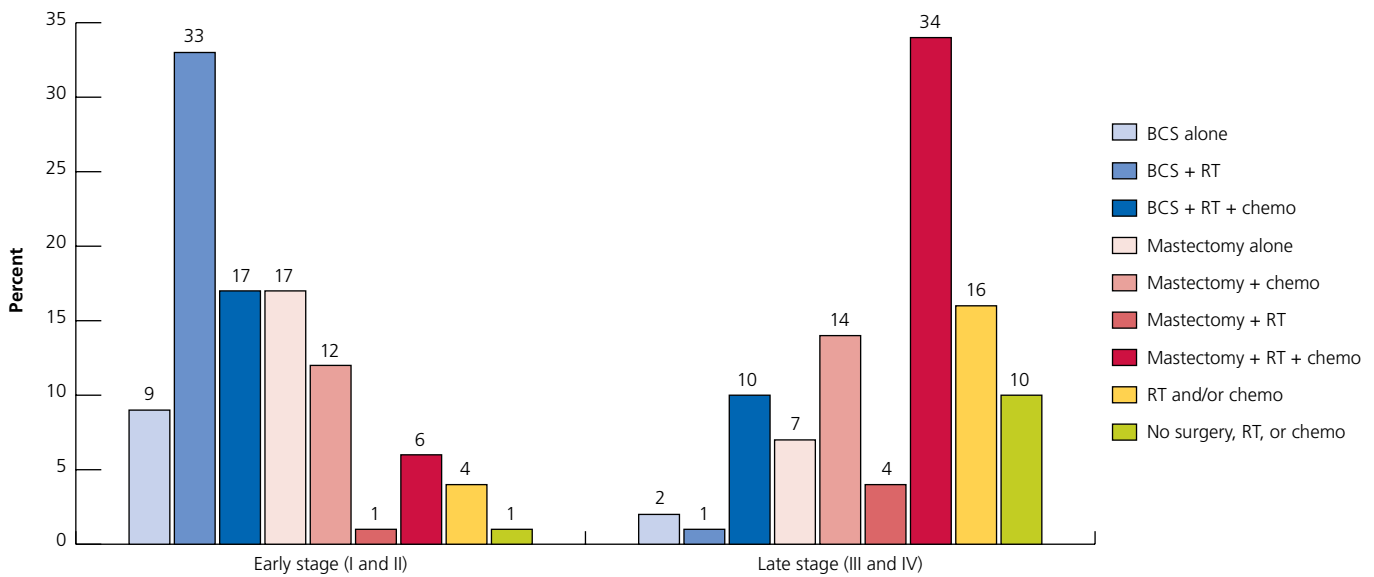


Stage categories do not sum to 100% because sufficient information is not available to stage all cancers.

Source: Howlander, et al, 2013.²⁵

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Figure 4. Female Breast Cancer Treatment Patterns (%), by Stage, 2011



BCS = breast-conserving surgery; RT = radiation therapy; Chemo = chemotherapy and includes targeted therapy and immunotherapy drugs.

Source: National Cancer Data Base, 2011.³⁸

American Cancer Society, Surveillance and Health Services Research, 2014

exemestane [Aromasin]) for at least 5 years.⁵ Hormone therapy is generally started after chemotherapy and radiation are complete (if they were needed). Other hormone therapy drugs (e.g., fulvestrant [Faslodex], LHRH analogs) are available for treatment of advanced disease.

For women whose cancer tests positive for HER2, a number of drugs that target the HER2 protein are available. Some, like trastuzumab (Herceptin) and pertuzumab (Perjeta), can be used to treat early or late-stage disease, while others, such as lapatinib (Tykerb) and ado-trastuzumab emtansine (Kadcyla), are only used for advanced disease. By attaching to the HER2 receptor, targeted therapies block the spread and growth of cancer. Targeted therapies can be given as single agents or in combination with chemotherapy or hormone therapy.

The overall 5-year relative survival rate for female breast cancer patients has improved from 75% between 1975 to 1977 to 90% for 2003 through 2009. This increase is due largely to improvements in treatment (i.e., chemotherapy, hormone therapy, and targeted drugs) and to earlier diagnosis resulting from the widespread use of mammography.⁶

The 5-year relative survival for women diagnosed with localized breast cancer is 99%; if the cancer has spread to nearby tissues or lymph nodes (regional stage) or distant lymph nodes or organs (distant stage), the survival rate falls to 84% or 24%, respectively (Figure 5). For all stages combined, relative survival rates at 10 and 15 years after diagnosis are 83% and 78%, respectively. Caution should be used when interpreting long-term survival rates because they represent patients who were diagnosed many years

ago and do not reflect recent advances in detection and treatment. In addition to stage, cancer-related factors that influence survival include tumor grade, hormone receptor status, and HER2 status.

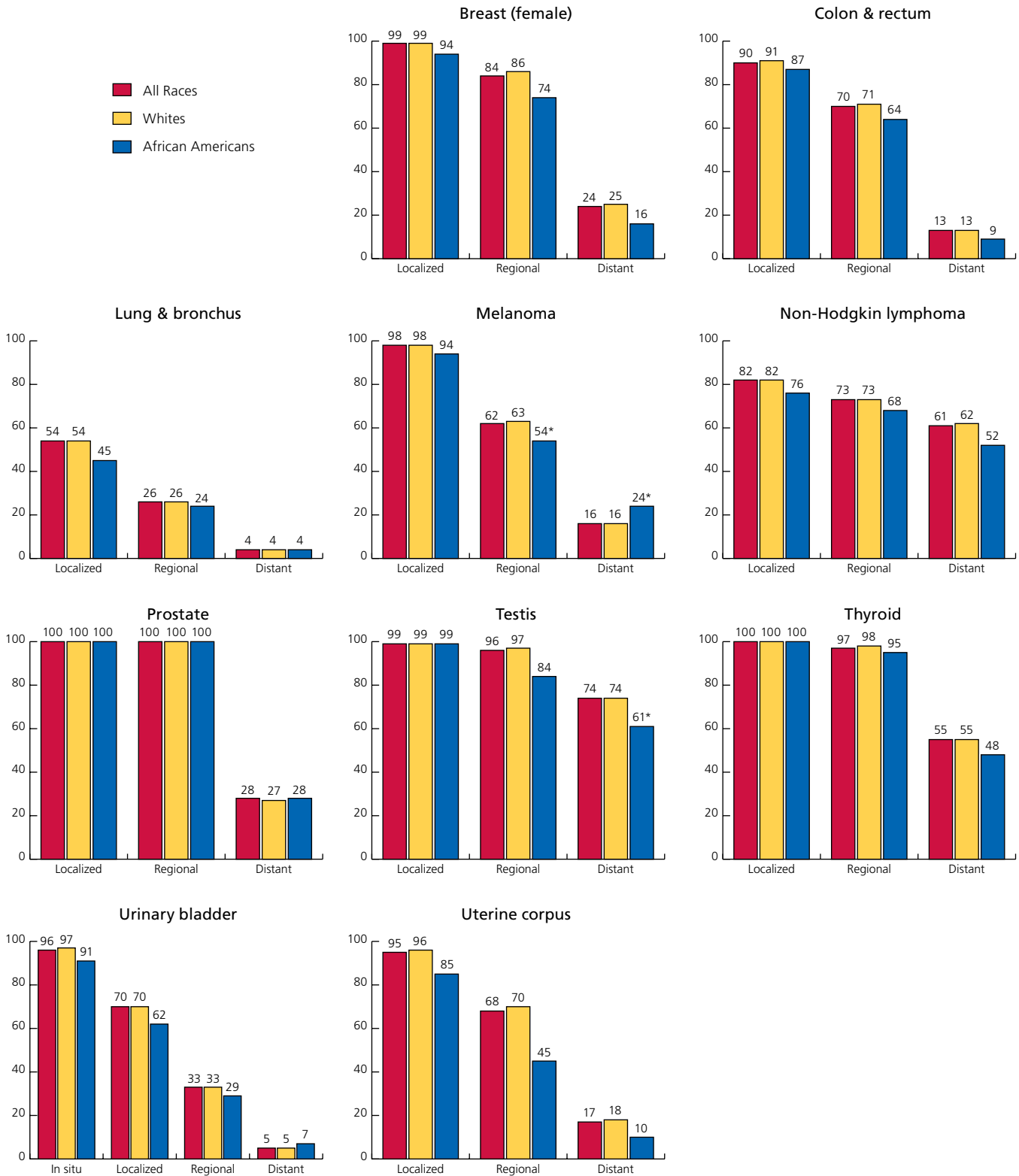
Black women are less likely than white women to be diagnosed with local-stage breast cancer (Figure 3, page 5) and generally have lower survival than white women within each stage (Figure 5). The reasons for these differences are complex but may be explained in large part by socioeconomic factors, less access and utilization of quality medical care among black women, and biological differences in cancers.⁷⁻⁹

Common concerns of breast cancer survivors

Lymphedema of the arm is swelling due to the buildup of lymph fluid in the tissue just under the skin caused by removal of or damage to the axillary (underarm) lymph nodes. It is a common side effect of both breast cancer surgery and radiation therapy that can develop soon after treatment or even years later. It has been estimated that about 20% of women who undergo axillary lymph node dissection and about 6% of women who have SLNB will develop arm lymphedema.¹⁰ Some evidence suggests that upper body exercises and other forms of cancer rehabilitation may reduce the risk and lessen the severity of this condition.^{11,12} For more information about impairment-driven cancer rehabilitation, see page 25.

Other long-term local effects of surgical and radiation treatment include numbness, tingling, or tightness in the chest wall, arms, or shoulders. Some women have persistent nerve (neuropathic)

Figure 5. Five-year Relative Survival Rates (%) among Patients Diagnosed with Select Cancers by Race and Stage at Diagnosis, 2003-2009



*The standard error of the survival rate is between 5 and 10 percentage points.

Source: Howlader, et al, 2013.²⁵

pain in the chest wall, armpit, and/or arm after surgery. Although this is called post-mastectomy pain syndrome because it was first described in women who had mastectomies, it can occur after breast-conserving therapy as well. Studies have shown that between 25% and 60% of women develop chronic pain after breast cancer treatment.¹³ In addition, women diagnosed and treated for breast cancer at younger ages may experience impaired fertility and premature menopause and are at an increased risk of osteoporosis.¹⁴ Treatment with aromatase inhibitors can also cause osteoporosis, as well as muscle pain, and joint stiffness and/or pain.¹⁵ Some breast cancer patients also experience mental impairments, chronic fatigue, hot flashes, and vaginal dryness.¹⁶

For more information about breast cancer, see *Breast Cancer Facts & Figures*, available online at cancer.org/statistics.

Cancers in Children and Adolescents

About 1% of all new cancer diagnoses occur in children and adolescents. It is estimated that there were 60,620 cancer survivors ages 0-14 years (children) and 48,690 survivors ages 15-19 (adolescents) living in the US as of January 1, 2014, and an additional 10,450 children and 5,330 adolescents will be diagnosed in 2014. A detailed report on childhood and adolescent cancers was published earlier this year as a special section in the Society's Cancer Facts & Figures 2014, available online at cancer.org/statistics.

The types of cancer most commonly diagnosed in children differ from those in adults.

Cancers that are most common in children ages 0-14 are:

- Acute lymphocytic leukemia (ALL) (26%)
- Brain and central nervous system (CNS) tumors (21%)
- Neuroblastoma (7%)

The three most common cancers among adolescents ages 15-19 are:

- Hodgkin lymphoma (15%)
- Thyroid carcinoma (11%)
- Brain and CNS tumors (10%)

Some other common pediatric cancers include:

- Non-Hodgkin lymphoma (NHL), which accounts for 62% of lymphomas in children and 35% of lymphomas in adolescents¹⁷
- Wilms tumor, a kidney cancer that usually occurs in children under age 6 and may be recognized as a swelling in the abdomen
- Acute myeloid leukemia, a cancer that arises from blood-forming cells and is most common during the first two years of life
- Rhabdomyosarcoma, a soft-tissue sarcoma that most often occurs in the head and neck, genitourinary area, and extremities

- Retinoblastoma, an eye cancer that is typically recognized because of discoloration of the eye pupil and usually occurs in children younger than 5 years of age
- Osteosarcoma, a bone cancer that most often occurs in adolescents and commonly appears as sporadic pain in the affected bone
- Ewing sarcoma, another type of cancer that usually arises in the bone, is most common in adolescents, and typically appears as pain at the tumor site.

Treatment and survival

Pediatric cancers can be treated with a combination of therapies (surgery, radiation, chemotherapy, and targeted therapy) chosen based on the type and stage of the cancer. Treatment most commonly occurs in specialized centers and is coordinated by a team of experts, including pediatric oncologists and surgeons, pediatric nurses, social workers, psychologists, and others.

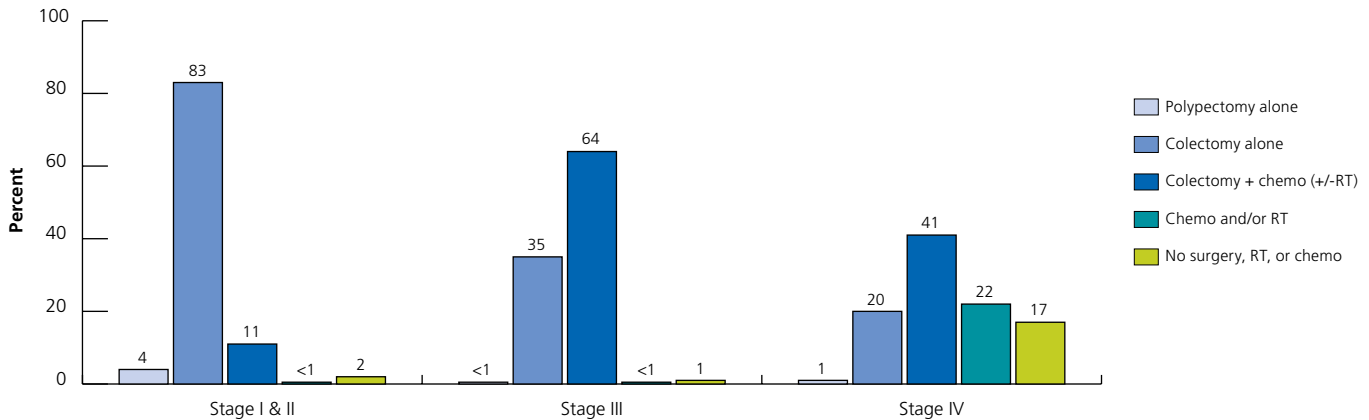
Pediatric cancer survival rates vary considerably depending on cancer type, patient age, and other characteristics. For example, the 5-year relative survival rate is 98% for retinoblastoma, 97% for Hodgkin lymphoma, 90% for Wilms tumor, 89% for ALL, 87% for NHL, 78% for neuroblastoma, 72% for brain and CNS tumors, 71% for osteosarcoma, and 67% for rhabdomyosarcoma. The 5-year relative survival rate for all childhood cancers (ages 0-14) combined has improved markedly over the past 30 years, from 58% for cases diagnosed between 1975-1979 to 83% for cases diagnosed during 2003-2009, due to new and improved treatments.

Common concerns of childhood cancer survivors

Children diagnosed with cancer may experience treatment-related side effects not only during treatment, but many years later as well. Aggressive treatments used for childhood cancers, especially in the 1970s and 1980s, resulted in a number of late effects, including an increased risk of second cancers. A large follow-up study of pediatric cancer survivors found that almost 10% developed a second cancer over the 30-year period following initial diagnosis – most commonly female breast, thyroid, and brain and other CNS tumors.¹⁸ Even many newer, less toxic, therapies increase the risk of serious health conditions in long-term childhood cancer survivors.¹⁹ A recent study found among childhood cancer survivors exposed to cancer treatments that were potentially toxic to the heart or lungs, more than half experience cardiac or pulmonary problems.¹⁹

It is important that survivors of pediatric cancers are monitored for long-term and late effects. The Children's Oncology Group (COG), a National Cancer Institute-supported clinical trials group that cares for more than 90% of US children and adolescents diagnosed with cancer, has developed long-term follow-up guidelines for screening and management of late effects in survivors of childhood cancer. For more information on childhood cancer management, see the COG Web site at survivorship-guidelines.org.

Figure 6. Colon Cancer Treatment Patterns (%), by Stage, 2011



Chemo = chemotherapy and includes targeted therapy and immunotherapy drugs; RT = radiation therapy.

Source: National Cancer Data Base, 2011.³⁸

American Cancer Society, Surveillance and Health Services Research, 2014

Common concerns of adolescent cancer survivors

Cancers occurring in adolescents (ages 15 to 19 years) are associated with a unique set of issues. Adolescents diagnosed with cancers that are more common in childhood are usually most appropriately treated at pediatric facilities or by pediatric specialists rather than by adult-care specialists. Childhood cancer centers are more likely than adult cancer centers to offer patients the opportunity to participate in clinical trials.²⁰ Studies have shown that for adolescent patients diagnosed with ALL, outcomes are improved on pediatric, as opposed to adult, protocols.^{21, 22} However, for teen patients with cancers that are more common among adults, such as melanoma, testicular, and thyroid cancers, treatment by adult-care specialists is more appropriate.²³ Studies have found that improvements in survival among adolescents have not been as dramatic as those seen in children or even those observed for some older adult patients; however, the current overall 5-year relative survival rate for adolescents (85%) is similar to that for children (83%).^{24, 25}

Colon and Rectum

It is estimated that as of January 1, 2014, there were more than 1.2 million men and women living in the US with a previous colorectal cancer diagnosis, and an additional 136,830 will be diagnosed in 2014. The median age at diagnosis for colorectal cancer is 67 for males and 71 for females.

Use of recommended colorectal cancer screening tests can both detect cancer earlier and prevent colorectal cancer through the detection and removal of precancerous polyps. However, only 59% of men and women 50 years of age and older received colorectal cancer screening according to guidelines in 2010.²⁶

Treatment and survival

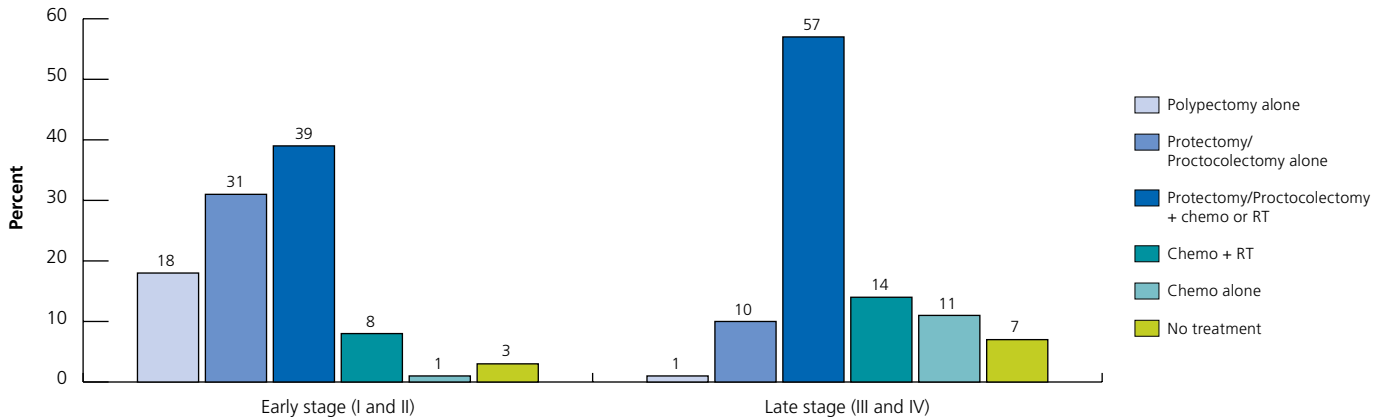
Treatment for cancers of the colon and rectum varies by tumor location and stage at diagnosis. Surgical procedures for colorectal cancer include polypectomy (removal of polyps), colectomy (removal of all or part of the colon), proctectomy (removal of the rectum), and proctocolectomy (removal of the rectum and all or part of the colon). Surgery to remove the cancer and nearby lymph nodes is the most common treatment for early stage (I and II) colon (98%) and rectal (88%) cancer (Figures 6 and 7, page 10). A colostomy (creation of an abdominal opening for elimination of body waste) may also be needed, although it is often temporary, until the colon or rectum heals from surgery. In a procedure called colostomy reversal surgery, the opening is closed and the ends of the intestine are reconnected after the patient has healed from the original surgery. Rectal cancer patients require a colostomy more often than colon cancer patients, 29% versus 12%, respectively.²⁷ Approximately 1 in 8 people with rectal cancer requires a permanent colostomy.²⁸

For stage III and some stage II colon cancers, surgery is followed by about 6 months of chemotherapy to lower the risk of recurrence. In contrast, stage II and III rectal cancers are often treated with chemotherapy combined with radiation therapy before surgery (neoadjuvant).

Chemotherapy is often the main treatment for advanced colon or rectal cancers. A number of targeted drugs are also available to treat metastatic colorectal cancer.

The 1- and 5-year relative survival rates for persons with colorectal cancer are 83% and 65%, respectively. Survival continues to decline to 58% at 10 years after diagnosis. When colorectal cancer is detected at an early stage, the 5-year relative survival rate is 90%

Figure 7. Rectal Cancer Treatment Patterns (%), by Stage, 2011



Chemo = chemotherapy and includes targeted therapy and immunotherapy drugs; RT = radiation therapy.

Source: National Cancer Data Base, 2011.³⁸

American Cancer Society, Surveillance and Health Services Research, 2014

(Figure 5, page 7); however, only 40% of cases are diagnosed at this stage (Figure 3, page 5), in part due to the underuse of screening. After the cancer has spread regionally to involve nearby organs or lymph nodes, the 5-year survival drops to 70%. When the disease has spread to distant organs, 5-year survival is 13%.

Common concerns for colorectal cancer survivors

Most long-term survivors of colorectal cancer report psychological quality of life comparable to that of the general population, but a somewhat lower physical quality of life.²⁹ Bowel dysfunction is particularly common, especially among those diagnosed with late-stage cancer. Cancer recurrence is not uncommon among colorectal survivors; about half of surgically treated patients will experience a recurrence in the first three years after surgery.³⁰ Colorectal cancer survivors are also at increased risk of second primary cancers of the colon and rectum, as well as other cancer sites, especially those within the digestive system.³¹

For more information about colorectal cancer, see *Colorectal Cancer Facts & Figures*, available online at cancer.org/statistics.

Leukemias and Lymphomas

It is estimated that as of January 1, 2014, there were 316,210 leukemia survivors living in the US, and an additional 52,380 people will be diagnosed with leukemia in 2014. Leukemia is a cancer of the bone marrow and blood. Most leukemias can be classified into one of four main groups according to cell type and rate of growth: acute lymphocytic leukemia (ALL), chronic lymphocytic leukemia (CLL), acute myeloid leukemia (AML), and chronic myeloid leukemia (CML).

The majority (91%) of leukemia patients are diagnosed at age 20 and older; AML and CLL are the most common types of leukemia in adults. Before age 20, ALL is most common, accounting for 80% of leukemias in children and 56% of leukemia cases in adolescents. The median age at diagnosis for ALL is 14 years; the median ages at diagnosis for CLL, AML, and CML are 71, 67, and 64, respectively (Figure 2, page 4).

Lymphomas are cancers that begin in cells of the immune system called lymphocytes. There are two types of lymphomas: Hodgkin lymphoma (HL) and non-Hodgkin lymphoma (NHL). NHLs can be further divided into indolent and aggressive categories, each of which includes many subtypes that progress and respond differently to treatment. It is estimated that as of January 1, 2014, there were 197,850 HL survivors and 569,820 NHL survivors, and that 9,190 and 70,800 new cases of HL and NHL, respectively, will be diagnosed in 2014.

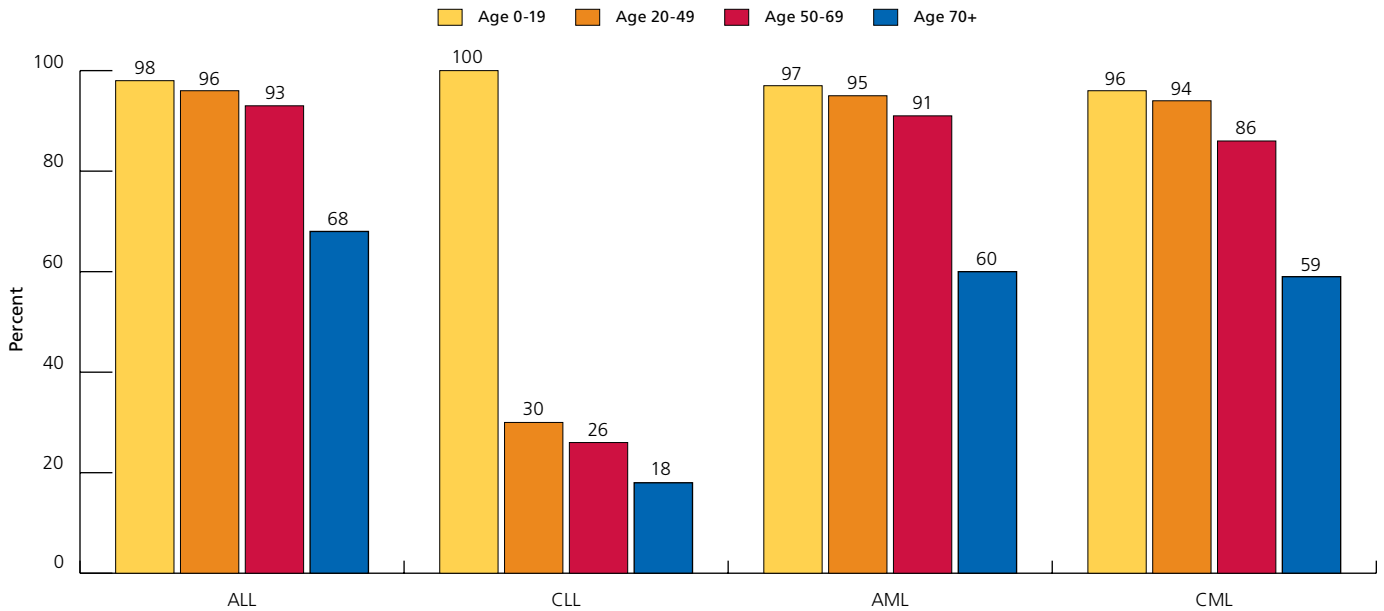
Both HL and NHL can occur at any age; however, the majority (64%) of HL occurs before age 50, whereas most cases of NHL (83%) occur in those ages 50 and older (Figure 2, page 4).

Treatment and survival

AML. Acute myeloid leukemia (also called acute myelogenous leukemia) arises from blood-forming cells, most often those that would turn into white blood cells (except lymphocytes). It is called acute because it is rapidly fatal in the absence of treatment.

Chemotherapy is the standard treatment for AML (Figure 8), but many older adults (among whom the disease is most common) are not able to tolerate the most aggressive and effective regimens. Some patients may also undergo stem cell transplantation, and some receive radiation therapy (often as part of a conditioning

Figure 8. Chemotherapy Use (%) among Leukemia Patients by Age, 2011



Note: Chemotherapy includes targeted therapy and immunotherapy drugs.

Source: National Cancer Data Base, 2011.³⁸

American Cancer Society, Surveillance and Health Services Research, 2014

regimen prior to stem cell transplantation). Treatment has two phases. The first, called induction, is designed to clear the blood of leukemia cells and put the disease into remission (which means that leukemia cells are not seen in pathologic examinations of the blood and bone marrow). Induction usually kills most of the cancer cells. The goal of the second phase, called consolidation, is to kill any remaining leukemia cells that would cause relapse if left untreated. Approximately 60%-70% of adults with AML can expect to attain complete remission status following the first phase of treatment, and more than 25% of adults survive 3 or more years and may be cured.³² About 3% of AML cases occur in children ages 14 and younger, for whom the prognosis is substantially better than among adults in part because children tend to respond better to chemotherapy. Survival for AML decreases markedly with age. The 5-year relative survival rate for children and adolescents (ages 0 to 19 years) is 63%, but it declines to 49%, 28%, and 5% for patients ages 20 to 49 years, 50 to 65 years, and 65 years and older, respectively.³³

CML. Chronic myeloid leukemia (also called chronic myelogenous leukemia) is a type of cancer that starts in the blood-forming cells of the bone marrow and invades the blood. Once suspected, CML is usually easily diagnosed because the involved cells have a distinctive chromosomal abnormality called the Philadelphia chromosome. There are three phases of CML: chronic, accelerated, and blast phases. The chronic phase is the least aggressive and is characterized by no or mild symptoms; the accelerated

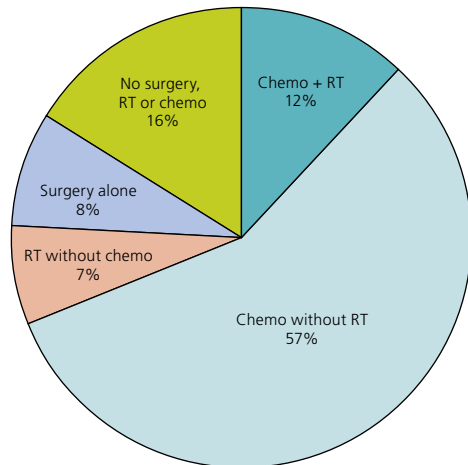
phase has noticeable symptoms such as fever, poor appetite, and fatigue; the cancer is most aggressive in the blast phase, which has more severe symptoms and may rapidly lead to death.

The current standard of care for CML is to treat with a type of targeted drug called a tyrosine kinase inhibitor (such as imatinib [Gleevec]). These drugs are very effective at inducing remission and decreasing progression to the accelerated phase, but must be taken continuously to keep the disease in check. In part due to the discovery of these targeted therapies, the 5-year survival rate for CML has nearly doubled from 31% for patients diagnosed during 1990-1992 to 59% for those diagnosed during 2003-2009.²⁵

ALL. Acute lymphocytic leukemia (also called acute lymphoblastic leukemia) is a disease in which too many immature lymphocytes (type of white blood cell) are produced in the bone marrow. It progresses rapidly without treatment. Although ALL is the most common type of leukemia diagnosed in children, accounting for 80% of all childhood (ages 0 to 14 years) leukemia cases, 49% of cases are diagnosed in patients ages 20 years and older.³⁴

Treatment is generally in three phases and consists of 4-6 weeks of induction chemotherapy (given to induce remission) often administered in the hospital, followed by several months of consolidation (or intensification) and 2-3 years of maintenance chemotherapy. The cancer cells of some ALL patients have a chromosomal abnormality known as the Philadelphia chromo-

Figure 9. Non-Hodgkin Lymphoma Treatment Patterns (%), 2011



Cemo = chemotherapy and includes targeted therapy and immunotherapy drugs; RT= radiation therapy.

Source: National Cancer Data Base, 2011.³⁸

American Cancer Society, Surveillance and Health Services Research, 2014

some, like that seen in CML; these patients benefit from the addition of a targeted drug such as imatinib (Gleevec) to chemotherapy. More than 95% of children and 78%-92% of adults with ALL attain remission.³⁵ Allogeneic bone marrow transplantation (the transplanted cells come from a donor whose tissue type closely matches the patient's) is recommended for some whose leukemia has high-risk characteristics at diagnosis and for those who relapse after remission. It may also be used if the leukemia does not go into remission after successive courses of induction chemotherapy.

Survival rates for patients with ALL have increased significantly over the past 3 decades, particularly among children. For example, the 5-year relative survival rate for children (ages 0-14) increased from 57% in the mid-1970s to 92% in 2003-2009.²⁵ Previous studies have also documented lower survival rates for black children with ALL compared to white children.³⁶ Notably, the black-white survival disparity in children and adolescents has diminished in recent years from a 21% difference in 5-year survival for ALL during 1980-1984 (47% vs 68%, respectively) to a 6% difference during 2003-2009 (84% vs. 90%, respectively).¹⁷ Survival declines with increasing age; the current 5-year survival rate is 42% for ages 20-39, 28% for ages 40-64, and 12% for ages 65+.

CLL. Chronic lymphocytic leukemia is characterized by the overabundance of mature lymphocytes in the blood and bone marrow. It usually progresses slowly and is the most common type of leukemia in adults, with 95% of cases occurring in those ages 50 and older (Figure 2, page 4). Treatment is not likely to cure CLL and it is not clear that it extends survival, thus it is

generally reserved for symptomatic patients or those who have low blood cell counts or other complications. For patients with uncomplicated early disease, active surveillance (carefully monitoring disease progression over time) is a common treatment approach. It should be noted that the low rates of chemotherapy shown for CLL in Figure 8, page 11, are for the first course of treatment only and do not reflect those patients who receive chemotherapy later in the course of disease. For patients with more advanced disease, available treatments include chemotherapy, immunotherapy, targeted therapy, radiation therapy, and surgery (removal of the spleen). The overall 5-year relative survival for CLL is 79%; however, there is a large variation in survival among individual patients, ranging from several months to normal life expectancy.²⁵

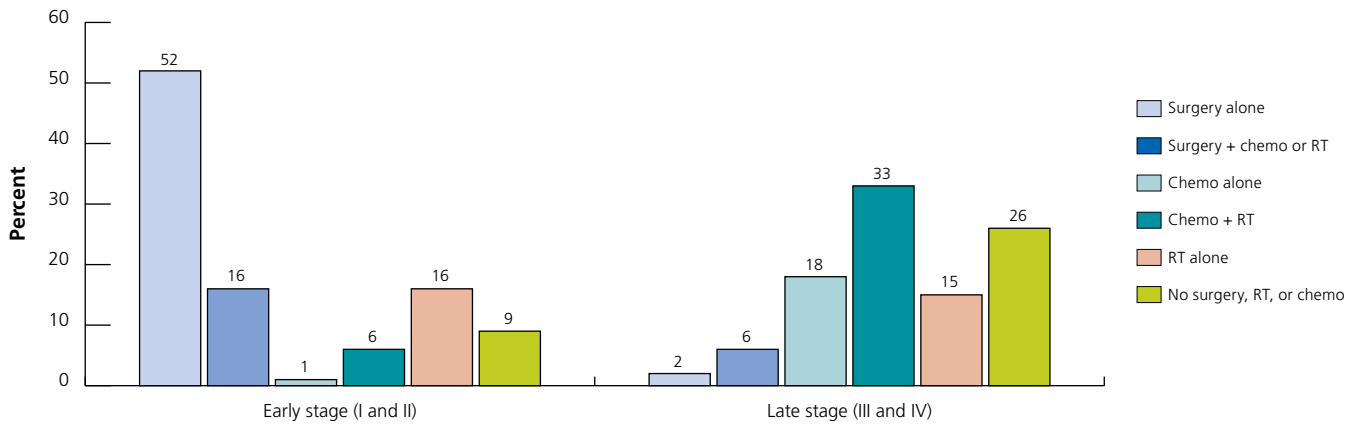
HL. HL is a cancer of the lymph nodes that often starts in the chest, neck, or abdomen. It can be diagnosed at any age, but is most common in early adulthood (60% of cases are diagnosed between ages 15 and 49, Figure 2, page 4). There are two major types of HL. Classical HL is the most common and is distinguishable by the presence of Reed Sternberg cells. Nodular lymphocyte-predominant HL (NLPHL) is rare, comprising only about 5% of HL cases and is characterized by "popcorn" cells.³⁴ NLPHL is a more slow-growing disease with a generally favorable prognosis.³⁷

Classical HL is generally treated with multi-agent chemotherapy (81%), sometimes in combination with radiation therapy (32% among chemotherapy recipients), though the use of radiotherapy is declining.³⁸ Stem cell transplantation may be an option if these are not effective. The targeted drug brentuximab vedotin (Adcetris) – a monoclonal antibody linked to a chemotherapy drug – is used to treat Hodgkin lymphoma (as well as a rare form of NHL) in patients whose disease has failed to respond to other treatment. For patients with NLPHL, radiation therapy alone may be appropriate for early stage disease. For those with later-stage disease, chemotherapy plus radiation, as well as the monoclonal antibody rituximab, may be recommended.

The 5-year relative survival rate for all HL combined has improved from 72% for cases diagnosed from 1975-1977 to 88% for those diagnosed from 2003-2009.²⁵ The current 1-year and 10-year survival rates are 92% and 80%, respectively. The overall 5-year relative survival rate is 96% for NLPHL and 85% for CHL.²⁵

NHL. The most common types of NHL are diffuse large B-cell lymphoma (DLBCL), representing 37% of cases, and follicular lymphoma, representing 20% of cases.³⁴ DLBCLs grow quickly, yet most patients with localized disease and about 50% with advanced-stage disease are cured.^{39, 40} Follicular lymphomas tend to grow slowly and often do not require treatment until the lymphoma causes symptoms; however, many are not curable. Some cases of follicular lymphoma transform into DLBCL.⁴¹ Burkitt lymphoma is a much less common and very fast-growing lymphoma; however it is often curable with intense treatment.⁴²

Figure 10. Non-small Cell Lung Cancer Treatment Patterns (%), by Stage, 2011



Chemo = chemotherapy and includes targeted therapy and immunotherapy drugs; RT = radiation therapy.

Source: National Cancer Data Base, 2011.³⁸

American Cancer Society, Surveillance and Health Services Research, 2014

NHL is usually treated with chemotherapy, which is often combined with highly specific monoclonal antibodies that are directed at lymphoma cells such as rituximab (Rituxan) and alemtuzumab (Campath). Approximately 69% of NHL patients receive chemotherapy (including monoclonal antibody therapy) including 12% who also receive radiation therapy (Figure 9). Radiation alone is used less often (7%) and about 16% of patients receive no initial treatment. If NHL persists or recurs after standard treatment, stem cell transplantation may be an option.

The overall 5-year relative survival rate is 69%; by subtype, the 5-year survival rate is 85% for follicular lymphoma, 61% for DLBCL, and 57% for Burkitt lymphoma.²⁵

Special concerns of leukemia and lymphoma survivors

Treatments for leukemia and lymphoma can result in a number of significant late effects. In the past, some children with ALL received cranial radiation therapy to treat any spread of leukemia to the central nervous system (CNS). This treatment can cause long-term cognitive deficits and is rarely used today. Chest radiation for Hodgkin lymphoma increases the risk for developing various heart complications (e.g., valvular heart disease and coronary artery disease), as well as breast cancer among women. Some leukemia and lymphoma survivors have problems with recurrent infections and low blood cell counts, which may require blood transfusions.

Several forms of leukemia and lymphoma in adults may initially progress very slowly or remain in remission for long periods. While this period of relatively healthy survivorship is most welcome, it may pose unique challenges to patients and their loved ones due to anxiety about eventual disease progression or recurrence.

Lung and Bronchus

It is estimated that there were 430,090 men and women living in the US with a history of lung cancer as of January 1, 2014, and an additional 224,210 will be diagnosed in 2014. The median age at diagnosis for lung cancer is 70.

The majority of lung cancers (57%) are diagnosed after the cancer has spread to other parts of the body because symptoms usually do not appear until the disease is already in an advanced stage (Figure 3, page 5).

Much research has focused on identifying effective methods for detecting lung cancer at early stages. In 2010, results from the National Lung Screening Trial (NLST) showed 20% fewer lung cancer deaths among current and former heavy smokers who were screened with spiral computed tomography (CT scans) compared to standard chest x-ray.⁴³ In January 2013, the American Cancer Society issued guidelines for the early detection of lung cancer, which endorse a process of shared decision making between clinicians who have access to high-volume, high-quality lung cancer screening programs and current or former (quit within the previous 15 years) adult smokers with at least a 30-year pack history of smoking who are 55 to 74 years of age and in good health.⁴⁴ Shared decision making should include a discussion of the benefits, uncertainties, and harms associated with lung cancer screening.

Treatment and survival

Lung cancer is classified as small cell (13% of cases) or non-small cell (87%) for the purposes of treatment.³⁴ Based on type and stage of cancer, treatments include surgery, radiation therapy, chemotherapy, and targeted therapies.

Small cell lung cancer is an aggressive disease with about 70% of cases diagnosed with “extensive-stage” disease (cancers that have spread widely).⁴⁵ Most patients with small cell lung cancer receive chemotherapy. In addition, patients with “limited-stage” disease (which generally includes patients with cancer only on one side of the chest) often receive concurrent radiation therapy. Some patients also receive cranial radiation therapy to help prevent later development of brain metastases. Surgery is rarely part of the treatment for small cell lung cancer.

For patients with early stage non-small cell lung cancers, the majority (68%) undergo surgery, including 16% who also receive chemotherapy and/or radiation therapy (Figure 10, page 13). Most patients with advanced-stage non-small cell lung cancer are treated with chemotherapy and/or targeted therapies (18%), radiation therapy (15%), or a combination of these treatments (33%). There are a number of targeted drugs that can be used to treat advanced non-small cell lung cancer, including some that are only useful in treating cancers with certain gene mutations.

The 1-year relative survival for all lung cancers combined increased from 34% in 1975-1977 to 45% in 2006-2009, largely due to improvements in surgical techniques and combined therapies. The 5-year survival rate is 54% for cases detected when the disease is still localized, 26% for patients with regional disease, and 4% for patients with distant-stage disease (Figure 5, page 7). The overall 5-year survival for small cell lung cancer (6%) is lower than that for non-small cell (18%).²⁵

Special concerns for lung cancer survivors

Many lung cancer survivors have impaired lung function, especially if they have had surgery. In some cases respiratory therapy and medications can improve fitness and allow survivors to resume normal daily activities. Lung cancer survivors, particularly those who continue to smoke, are at an increased risk for additional smoking-related cancers, especially in the lung, head and neck, or urinary tract, as well as other health problems, and should be encouraged to quit. Survivors may feel stigmatized because of the social perception that lung cancer is a self-inflicted disease, which can be particularly difficult for lung cancer survivors who never smoked.⁴⁶

Melanoma

It is estimated that there were more than 1 million melanoma survivors living in the US as of January 1, 2014, and an additional 76,100 people will be diagnosed in 2014. Melanoma incidence rates have been increasing for at least 30 years.

About 84% of melanomas are diagnosed at a localized stage, when they are highly curable (Figure 3, page 5). The median age at diagnosis for melanoma is 64 for males and 57 for females. Although melanoma is rare before age 30, it is the second and fourth most commonly diagnosed cancer in women and men ages 20 to 29 years, respectively.³⁴

Treatment and survival

Surgery to remove the tumor and surrounding tissue is the primary treatment for most melanomas. Less than 3% of all patients with melanoma undergo radiation therapy.³³ However, almost one-half (45%) of patients with metastatic disease who receive either chemotherapy or immunotherapy also receive radiation therapy.³⁸ Patients with stage III melanoma are often offered adjuvant immunotherapy with interferon for about a year; however, this treatment has side effects that make it very difficult to tolerate. Treatment for patients with stage IV melanoma has changed in recent years and typically includes immunotherapy or targeted therapy drugs.

The 5- and 10-year relative survival rates for persons with melanoma are 91% and 89%, respectively. For those with localized melanoma, the 5-year survival rate is 98%; 5-year survival rates for individuals with regional and distant-stage diseases are 62% and 16%, respectively (Figure 5, page 7).

Special concerns for melanoma survivors

Depending on the size and location of the melanoma, removal of these cancers can be disfiguring. Men and women who are survivors of melanoma are nearly 13 and 16 times, respectively, more likely than the general population to develop additional melanomas due to skin type and other genetic risk factors and/or overexposure to ultraviolet radiation.⁴⁷ It is important for melanoma survivors to monitor their skin for new skin cancers and to limit sun exposure.

Prostate

It is estimated that there were nearly 3 million men with a history of prostate cancer living in the US as of January 1, 2014, and an additional 233,000 men will be diagnosed in 2014. The median age at diagnosis is 66 (Figure 2, page 4). Prostate is the most frequently diagnosed cancer in men aside from skin cancer. Most prostate cancers in the US are diagnosed by prostate-specific antigen (PSA) testing, although many expert groups, including the American Cancer Society, have concluded that data on the efficacy of PSA screening are insufficient to recommend routine use of this test.

Treatment and survival

Treatment options vary depending on stage and grade of the cancer, as well as patient characteristics such as age, other medical conditions, and personal preferences. Active surveillance (formerly known as “watchful waiting”) rather than immediate treatment is a reasonable and commonly recommended approach, especially for older men and those with less aggressive tumors and/or more serious comorbid conditions.⁴⁸⁻⁵⁰ Figure 11 describes the initial treatment for prostate cancer patients by age at diagnosis. More than half (52%) of men ages 64 or younger are initially treated with radical prostatectomy (removal of the

prostate along with nearby tissues) (Figure 11). Radiation therapy is the most common treatment for men ages 65 to 74 years (38%), whereas the majority of men ages 75 and older undergo active surveillance. Some men are treated with both surgery and radiation, and treatment may also involve hormonal therapy. Survival rates are favorable for patients with early stage disease treated with surgery or radiotherapy; however, both are associated with risks of physical impairments (sexual, urinary, and bowel).⁵¹⁻⁵³

More advanced prostate cancer may be treated with hormone (androgen deprivation) therapy, chemotherapy, bone-directed therapy (such as zoledronic acid or denosumab), radiation therapy, or a combination of these treatments. Hormone treatment is generally the first treatment used for advanced disease. It can often control the cancer for long periods, helping to relieve pain and other symptoms. An option for some men with advanced prostate cancer that is no longer responding to hormones is a cancer vaccine known as sipuleucel-T (Provenge).⁵⁴ For this treatment, special immune cells are removed from a man's body, exposed to prostate proteins in a lab, and then re-infused back into the body, where they attack prostate cancer cells. Newer, more effective forms of hormone therapy, such as abiraterone (Zytiga) and enzalutamide (Xtandi), have been shown to be beneficial for the treatment of metastatic disease.⁵⁵⁻⁵⁷ Radium-223 (Xofigo), a form of radiation therapy given as an injection into the blood, was recently approved to treat hormone-resistant prostate cancer that has spread to the bones.⁵⁸

Most (93%) prostate cancers are diagnosed in the local or regional stages, for which the 5-year relative survival rate approaches 100%. Over the past 25 years, the 5-year relative survival rate for all stages combined has increased from 68% to almost 100%. According to the most recent data, 10- and 15-year relative survival rates are 99% and 94%, respectively.

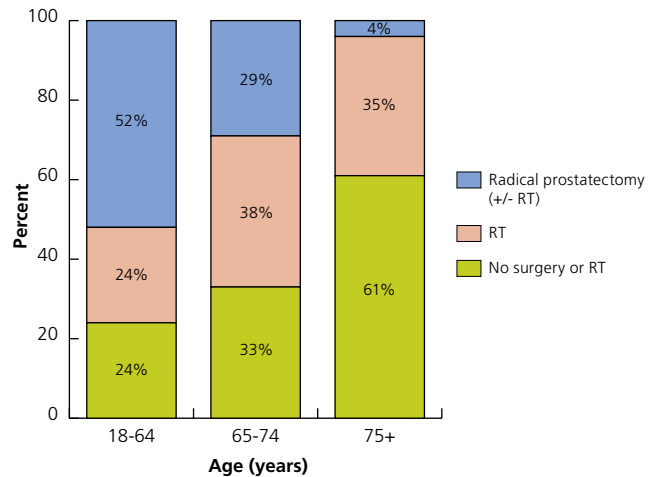
Special concerns for prostate cancer survivors

Many prostate cancer survivors who have been treated with surgery or radiation therapy experience incontinence, erectile dysfunction, and/or bowel complications.⁵⁹ Patients receiving hormonal treatment may experience loss of libido; menopausal-like symptoms including hot flashes, night sweats, and irritability; and breast development. Hormone therapy also increases the risk of anemia, osteoporosis, and metabolic syndrome, and may increase the risk of cardiovascular disease.⁶⁰

Testis

It is estimated that there were 244,110 testicular cancer survivors in the US as of January 1, 2014, and an additional 8,820 men will be diagnosed in 2014. Testicular germ cell tumors (TGCTs) account for more than 96% of testicular cancers.³⁴ These tumors arise from testicular cells that normally develop into sperm cells.

Figure 11. Prostate Cancer Primary Treatment Patterns (%), by Age, 2009-2011



RT = radiation therapy.

Source: Surveillance Epidemiology and End Results (SEER) Program, SEER 18 Registries, Division of Cancer Control and Population Science, National Cancer Institute.³³

American Cancer Society, Surveillance and Health Services Research, 2014

There are 2 main types of TGCTs: seminomas and nonseminomas. Nonseminomas generally occur among younger men (in their late teens to early 40s) and tend to be more aggressive. Seminomas are slow-growing and are generally diagnosed in men in their late 30s to early 50s. Most testicular cancers are detected early; a lump on the testicle is usually the first sign. Overall, 69% of patients are diagnosed at a localized stage (Figure 3, page 5).

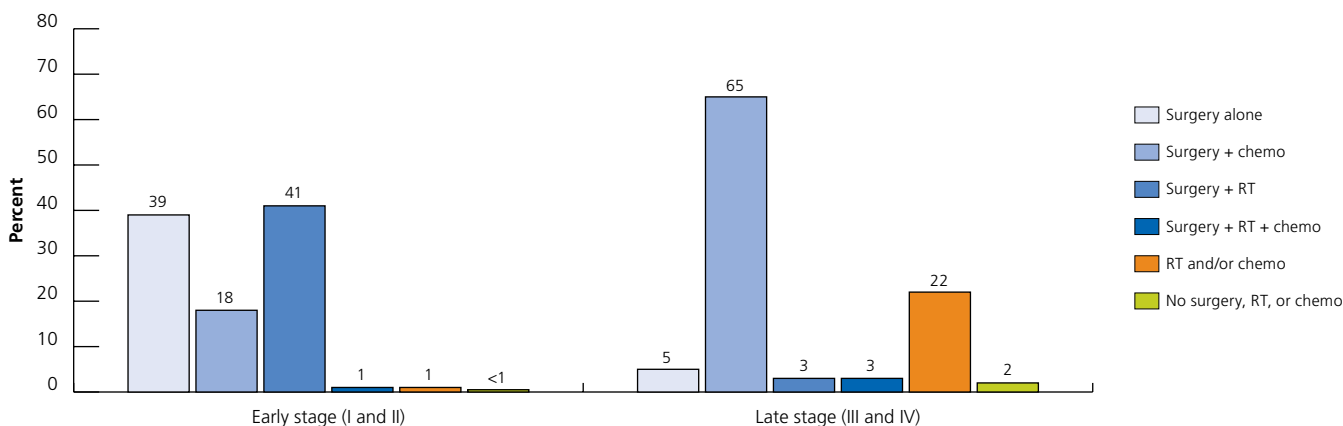
Treatment and survival

Treatment of almost all TGCTs begins with orchiectomy, a type of surgery involving the removal of the testicle in which the tumor arose. Subsequent treatment depends on stage and cancer type. After orchiectomy, early stage seminomas are often treated with radiation (42%) or active surveillance, with chemotherapy used less often (Figure 12, page 16). Over the past decade, post-surgery active surveillance has become an increasingly preferred management option for patients with stage I seminomas, and long-term study results support this treatment strategy.⁶¹ Late-stage seminomas are generally treated with surgery and chemotherapy (68%) (Figure 12, page 16).

Men with nonseminomas are often treated with chemotherapy after orchiectomy, especially at later stages (Figure 13, page 16). For men with early stage nonseminomas, approximately 22% undergo retroperitoneal lymph node dissection (RPLND), which is recommended to reduce the likelihood of recurrence.

For all testicular cancers combined, the 5-year relative survival rates are 99%, 96%, and 74% for tumors diagnosed at localized, regional, or distant stages, respectively (Figure 5, page 7).

Figure 12. Treatment Patterns (%) for Seminomatous Testicular Germ Cell Tumors, 2007-2011

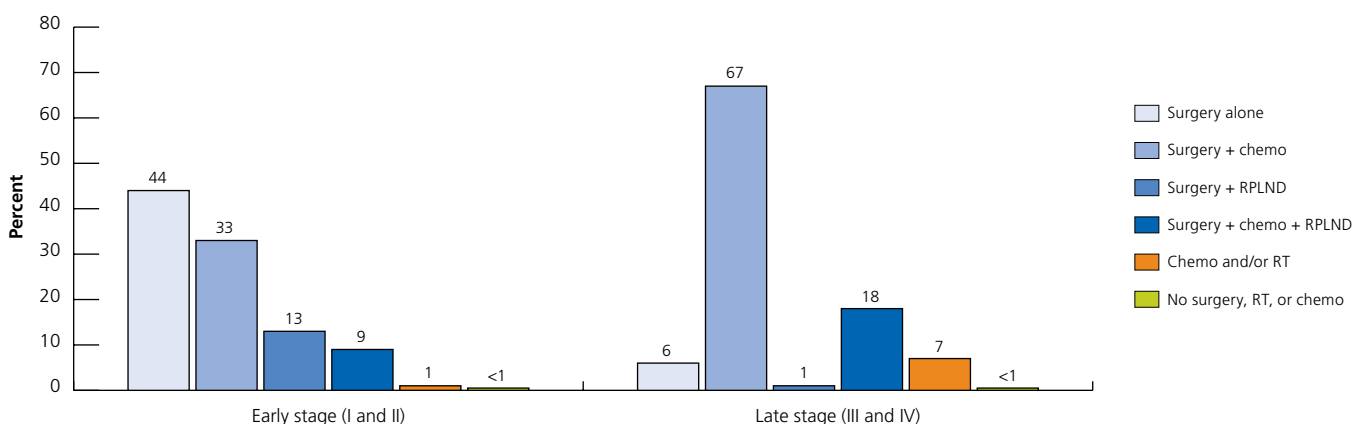


Chemo = chemotherapy and includes targeted therapy and immunotherapy drugs; RT = radiation therapy.

Source: National Cancer Data Base, 2011.³⁸

American Cancer Society, Surveillance and Health Services Research, 2014

Figure 13. Treatment Patterns (%) for Nonseminomatous Testicular Germ Cell Tumors, 2007-2011



Chemo = chemotherapy and includes targeted therapy and immunotherapy drugs; RPLND = retroperitoneal lymph node dissection.

Source: National Cancer Data Base, 2011.³⁸

American Cancer Society, Surveillance and Health Services Research, 2014

Special concerns of testicular cancer survivors

Testicular cancer survivors are often concerned about sexual and fertility problems after treatment. Although most men who have one healthy testicle produce sufficient male hormones and sperm to continue sexual relations and father children, sperm banking is recommended prior to treatment. Men with cancer in both testicles will require lifelong hormone replacement after treatment. Men treated with chemotherapy have increased risks of coronary artery disease as they age, and should be particularly mindful of risk factors such as high cholesterol, high blood pressure, obesity, and smoking.

Thyroid

It is estimated that there were 600,360 people living with a past diagnosis of thyroid cancer in the US as of January 1, 2014, and an additional 62,980 will be diagnosed in 2014. Thyroid cancer is the most rapidly increasing cancer in the US and has been increasing worldwide over the past few decades. The rise is thought to be primarily due to increased detection because of more sensitive diagnostic procedures, perhaps resulting in some overdiagnoses. However, some argue that the increase is in part real, and involves both small and large tumors.⁶²

Thyroid cancer commonly occurs at a younger age than most other adult cancers; the median age at diagnosis for thyroid cancer is 54 for males and 49 for females. Overall, 68% of thyroid patients are diagnosed at a localized stage; women are more likely to be diagnosed with local-stage tumors than men (71% versus 59%, respectively).²⁵

Treatment and survival

Most thyroid cancers are either papillary or follicular carcinomas, both of which are highly curable. About 3% of thyroid cancers are either medullary carcinoma or anaplastic carcinoma, which are more difficult to treat because they grow more quickly, have often metastasized by the time they are diagnosed, and do not respond to radioactive iodine treatment.³⁴

The first choice of treatment in nearly all cases is surgery, with patients receiving either total (84%) or partial (13%) thyroidectomy (removal of the thyroid gland).³⁸ Approximately 56% of surgically treated patients with well-differentiated (papillary or follicular) thyroid cancer receive radioactive iodine (I-131) after surgery to destroy any remaining thyroid tissue.⁶³ If the thyroid has been removed completely, thyroid hormone therapy (levothyroxine) is required and often given in a dosage high enough to inhibit the body from making thyroid-stimulating hormone, thereby decreasing the likelihood of recurrence.

Total thyroidectomy is the main treatment for patients with medullary thyroid cancer. When the tumor is extensive and invades many nearby tissues or cannot be completely removed, radiation therapy may be given after surgery to try to reduce the chance of recurrence in the neck. Anaplastic thyroid cancers are often widespread at the time of diagnosis, making surgery difficult or not possible. Radiation therapy alone or in combination with chemotherapy may be used to try and reduce the size of the tumor and allow for surgical removal.

The 5-year relative survival rate for all patients with thyroid cancer is 98%. However, survival varies by extent of disease, patient age at diagnosis, and the histologic type of cancer. The 5-year survival rate approaches 100% for localized disease, is 97% for regional-stage disease, and 55% for distant-stage disease. For all stages combined, survival declines with age at diagnosis: rates are nearly 100% for patients diagnosed before age 45 and 85% for those diagnosed at ages 75 or older.²⁵

Special concerns of thyroid cancer survivors

Patients receiving a thyroidectomy require thyroid hormone replacement pills and clinical monitoring to maintain proper hormone blood levels. Thyroid cancer survivors are often monitored for recurrence by measuring levels of thyroglobulin, a substance produced in the thyroid gland at high levels in people with papillary and follicular cancer. However, these levels are not useful in patients with high levels of anti-thyroglobulin antibodies, who are monitored through other means such as periodic

whole-body I-131 scans. Among patients thought to be cured after treatment, about 10%-30% experience recurrence or distant metastases.⁶⁴

About 25% of medullary thyroid cancers occur as part of a familial (genetic) syndrome, so patients with this cancer may be screened for other syndromic cancers and referred for genetic counseling and possible testing.

Urinary Bladder

It is estimated that there were 608,620 urinary bladder cancer survivors living in the US as of January 1, 2014, and an additional 74,690 cases will be diagnosed in 2014. Bladder cancer incidence is about 4 times higher in men than in women. Approximately 75% of patients with bladder cancer are diagnosed with non-muscle-invasive bladder cancer, that is the cancer is present only in the inner layer of bladder cells.⁶⁵ Cancer of the urinary bladder is most common among older adults. The median age at diagnosis is 73.

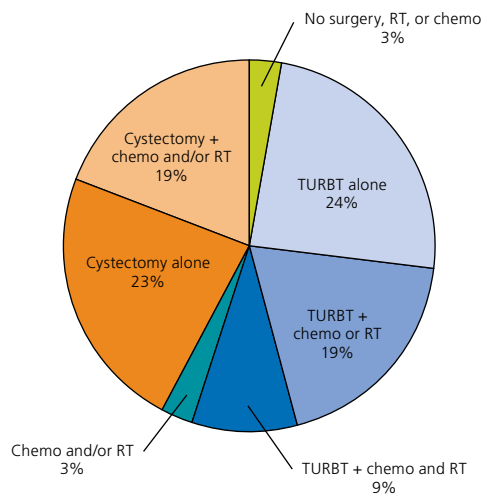
Treatment and survival

Treatment of urinary bladder cancer varies by stage and patient age. For non-muscle-invasive bladder cancer, most patients are diagnosed and treated with a minimally invasive procedure called transurethral resection of the bladder tumor or TURBT. This endoscopic surgery may be followed by intravesical treatment (injected directly into the bladder) with either a chemotherapy drug (18%) or the biological agent bacillus Calmette-Guerin (BCG) (25%).³⁸ BCG is a type of immunotherapy, which means it stimulates the body's own immune system to kill bladder cancer cells.

Among patients with muscle-invasive disease, 42% receive cystectomy, a surgery that removes all or part of the bladder, as well as the surrounding fatty tissue and lymph nodes, and nearly half of these patients also receive chemotherapy and/or radiation (Figure 14, page 18). Approximately 9% of patients receive TURBT combined with chemotherapy and radiation therapy. In appropriately selected cases, TURBT followed by combined chemotherapy and radiation therapy is as effective as cystectomy at preventing recurrence.⁶⁶⁻⁶⁸ Chemotherapy is usually the first treatment for advanced bladder cancers. If the cancer has not spread to other organs, patients may be offered chemotherapy either alone (32%) or in combination with radiation therapy (11%) before cystectomy.³⁸

For all stages combined, the 5-year relative survival rate is 78%.²⁵ Survival declines to 71% at 10 years and 67% at 15 years after diagnosis. In situ urinary bladder cancer is diagnosed in 51% of cases, for which the 5-year survival rate is 96%.²⁵ Patients with invasive tumors diagnosed at a localized stage have a 5-year survival rate of 70%; 35% of cancers are detected at this early stage. For those with regional and distant-stage disease, 5-year survival is 33% and 5%, respectively (Figure 5, page 7).

Figure 14. Muscle-invasive Bladder Cancer Treatment Patterns (%), 2011



RT = radiation therapy; Cystectomy = surgery that removes all or part of the bladder, as well as the surrounding fatty tissue and lymph nodes; TURBT = transurethral resection of the bladder tumor; Chemo = chemotherapy and includes targeted therapy and immunotherapy drugs.

Source: National Cancer Data Base, 2001.³⁸

American Cancer Society, Surveillance and Health Services Research, 2014

Special concerns of urinary bladder cancer survivors

Given the high rate of recurrence among bladder cancer patients (ranging from 50%-90%), attentive bladder cancer surveillance is very important.^{69,70} Surveillance includes cystoscopy (examination of the bladder with a small scope) and urine cytology, and may also include newer tests for markers such as NMP22 in the urine. Other tests may also be recommended for patients with muscle-invasive disease, such as chest x-rays and bladder washings.

Patients undergoing cystectomy require urinary diversion with either the construction of a “new” bladder (known as a neo-bladder) created using a small part of the intestine and connected to the urethra or a urostomy, which is a conduit that empties into a bag worn inside the abdomen. A recent study reported comparable outcomes with both techniques; however, a neo-bladder remains less common than urostomy (9% versus 91%).⁷¹ The neo-bladder procedure is more common among male patients and those who are younger, healthier, or treated at larger, higher volume hospitals.⁷¹ For those patients with muscle-invasive disease treated with chemotherapy and radiotherapy, most maintain full bladder function and good quality of life.⁷² However, these patients require careful surveillance with regular cystoscopy and a complete cystectomy if the cancer recurs.

Uterine Corpus

It is estimated that there were 624,890 uterine corpus (upper body of the uterus) cancer survivors living in the US as of January 1, 2014, and additional 52,630 women will be diagnosed in 2014. Uterine cancer is the second most common cancer among female cancer survivors, following breast cancer. Obese women are about 3 times more likely to develop uterine cancer than women of normal weight.⁷³ More than 90% of uterine cancers occur in the endometrium (lining of the uterus). Most uterine cancers (68%) are diagnosed at an early stage, usually because of postmenopausal bleeding. The median age at diagnosis for uterine corpus cancer is 61 (Figure 2, page 4).

Treatment and survival

Uterine cancers are usually treated with surgery, radiation, hormone therapy, and/or chemotherapy, depending on stage and histologic type. Surgery alone, consisting of hysterectomy (removal of the uterus, including the cervix), often along with bilateral salpingo-oophorectomy (removal of both ovaries and Fallopian tubes), is used to treat 72% of patients with early stage disease (Figure 15). About 26% of early stage patients have higher-risk disease and receive radiation therapy, either alone or in combination with chemotherapy, in addition to surgery.

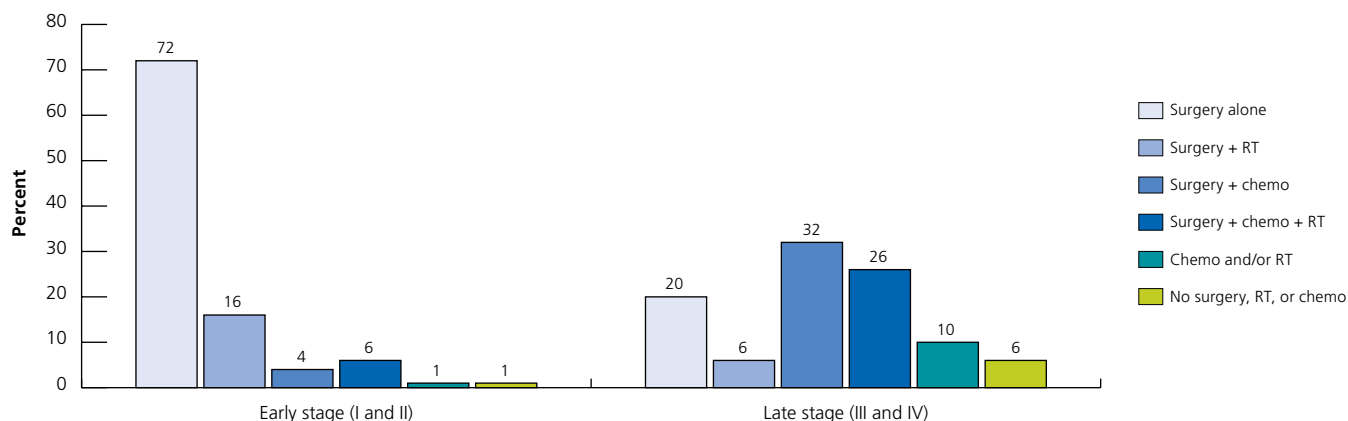
Among women with advanced-stage endometrial cancer, the majority (64%) receive surgery followed by radiation and/or chemotherapy (Figure 15). Clinical trials are currently assessing the most appropriate regimen of radiation and chemotherapy for women with metastatic or recurrent endometrial cancers.

The 1- and 5-year relative survival rates for uterine corpus cancer are 92% and 82%, respectively. The 5-year survival rates are 95% for localized disease, 68% for regional disease, and 17% for distant-stage disease (Figure 5, page 7). The overall 5-year survival for white women (84%) is 23 percentage points higher than that for black women (61%).²⁵ Higher body weight adversely affects endometrial cancer survival, whereas physical activity is associated with improved survival.⁷⁴

Special concerns of uterine corpus cancer survivors

Any hysterectomy causes infertility. Bilateral oophorectomy will cause menopause in premenopausal women, which can lead to symptoms such as hot flashes, night sweats, vaginal dryness, and osteoporosis. Sexual problems are commonly reported among uterine cancer survivors.⁷⁵ Removing lymph nodes in the pelvis can lead to a buildup of fluid in the legs (lymphedema). This occurs more often if radiation is given after surgery.⁷⁶

Figure 15. Uterine Cancer Treatment Patterns (%), by Stage, 2011



Chemo = chemotherapy and includes targeted therapy and immunotherapy drugs; RT = radiation therapy.

Source: National Cancer Database, 2011.³⁸

American Cancer Society, Surveillance and Health Services Research, 2014

Navigating the Cancer Experience: Diagnosis and Treatment

Newly diagnosed cancer patients and their families face numerous challenges. There are many difficult decisions to be made, from selecting a doctor and treatment facility to choosing between recommended treatment options. These demands are even more overwhelming for patients who experience barriers to quality cancer care.

Choosing a Doctor

Choosing an oncologist is one of the most important decisions for people who are newly diagnosed with cancer. Assistance is often needed because most patients have no experience in this area. The doctor who made the preliminary diagnosis, usually the patient's primary care physician, will often recommend appropriate cancer specialists.

There are three primary types of oncologists: medical, surgical, and radiation. Medical oncologists treat cancer using chemotherapy and other drugs. Surgical oncologists treat cancer with surgery. Radiation oncologists treat cancer with radiation therapy.

Some types of oncologists focus on specific populations. For example, pediatric oncologists specialize in the care of children, and hematologists specialize in patients with blood disorders. Some cancers, such as skin and prostate cancer, may be treated

by doctors who specialize in specific body systems (i.e., dermatologists and urologists, respectively). Plastic surgeons may also be involved in cancer-directed treatments and perform reconstructive surgeries that occur as part of cancer care, particularly for patients with breast or head and neck cancers.

Depending on the type of cancer and treatments recommended, the doctor overseeing the first course of treatment will likely be a surgeon, medical oncologist, or radiation oncologist. Regardless of which specialist sees the person first, doctors of the other specialties will likely be involved in planning and providing treatment and other aspects of care addressing patient and family quality of life concerns. Some oncology specialists participate in a multidisciplinary care team that consults regularly about cancer management in individual cases.

The American Society of Clinical Oncology, the world's leading professional organization representing physicians of all oncology subspecialties, has a searchable Web database of cancer specialists at cancer.net. Many other physician organizations have online physician databases, such as the American Society of Hematology, the Society of Surgical Oncology, the American Medical Association, the American College of Surgeons, the American Osteopathic Association, and the American Academy of Hospice and Palliative Medicine.

Goals for Improving the Quality of Cancer Care

In 2013, the Institute of Medicine released a new report titled *Delivering High-Quality Care: Charting a New Course for a System in Crisis*.⁷⁷ The committee identified 6 goals to improve the quality of cancer care:

- Engage patients and families in an informed medical decision-making process.
- Ensure an adequately staffed and trained cancer care team that provides coordinated care.
- Provide cancer care that is evidence-based.
- Develop a health care information technology system.
- Assess clinician performance and quality of care on an ongoing basis to inform and improve clinical practice.
- Ensure that high-quality cancer care is both accessible and affordable to all patients.

Once a list of potential specialists is identified, the patient should consider selecting a cancer specialist who:

- Is board-certified, thus demonstrating mastery of relevant knowledge and skills
- Has experience with their cancer type
- Accepts the patient's health insurance (most insurance plans have Web sites that can be searched for doctors by specialty)
- Has privileges at a hospital that is acceptable and approved by the patient's insurance

Finding this type of information may not be easy. Cancer patients should not hesitate to ask prospective doctors direct



questions about their level of experience, including the number of patients they have treated with the same type of cancer or the number of surgical procedures they have performed and their outcomes. They may also want to ask about how the doctor organizes cancer care with other members of the cancer treatment team (doctors and others, including specialists in areas such as psychosocial and palliative care), whether cases are presented at a cancer conference, and whether the doctor makes participation in clinical research trials an option to patients.

Choosing a Treatment Facility

There are many excellent cancer care centers throughout the United States, and a number of resources are available to learn about them.

Commission on Cancer

The Commission on Cancer (CoC), a program of the American College of Surgeons, has accredited more than 1,500 hospitals or facilities throughout the United States for their delivery of cancer care. Hospitals with this special designation have met certain standards regarding quality cancer care and offer a range of services. CoC-accredited cancer centers include major treatment centers as well as community hospitals that are staffed by a variety of specialists and generally provide high-quality diagnostic, staging, treatment, and symptom management services. However, some community hospitals may provide diagnostic and treatment services by referral only, and may not have board-certified specialists in all major oncology-related disciplines on staff. A searchable database is on their Web site (facs.org/cancerprogram) and includes information on the annual number of patients treated by cancer site.

National Cancer Institute

The National Cancer Institute (NCI) recognizes and funds two types of cancer centers that excel in research – basic and comprehensive cancer centers. NCI-designated basic cancer centers are required to conduct research in at least one of the following areas: laboratory, clinical, or population science. Comprehensive cancer centers must demonstrate expertise in all 3 research areas. In addition, they must initiate and conduct early phase innovative clinical trials and provide outreach and education for both health care professionals and the general public. Not all patients treated at these centers participate in research. A searchable list of the NCI-designated cancer centers is available on their Web site, cancercenters.cancer.gov.

Association of Community Cancer Centers

Founded in 1974, the Association of Community Cancer Centers (ACCC) has more than 700 member community cancer centers in the US. First published in 1988, ACCC's standards expand upon those of the American College of Surgeons' Commission on Cancer and outline the major components of a cancer program,

regardless of setting, and dictate how the components should relate to one another.

A searchable directory of the member community centers by state is available on their Web site, accancer.org/membership_directory.

Children's Oncology Group

The mission of the Children's Oncology Group (COG) is to cure and prevent childhood and adolescent cancer through scientific research and comprehensive care. More than 90% of children with cancer in the United States are treated at one of more than 200 affiliated centers. The COG currently has nearly 100 active clinical trials.

A listing of COG institutions by state can be found on their Web site, childrensoncologygroup.org

Choosing among Recommended Treatments

Quality cancer treatment strives to both extend survival and maintain quality of life.⁷⁷ Many factors are important in choosing among treatment options. The goal is to select the treatment that will most effectively eliminate the cancer while ensuring the highest possible level of physical and emotional well-being during and after treatment. Identifying what is important to patients and families in terms of their quality of life and other personal priorities is an essential early step in developing a treatment plan. Helpful information is available online at prepareforyourcare.org to assist patients and families in communicating with each other and their care team. See page 25 for more information on palliative care.

Treatment for cancer can involve surgery, chemotherapy, radiation, hormone therapy, immunotherapy, targeted therapy, and bone marrow transplantation. Palliative care, psychosocial care, and impairment-driven rehabilitation may also be built into the treatment plan to help minimize pain, symptoms, and distress; maximize functioning; and address other patient and family quality of life concerns. When it is anticipated that a cancer will grow or progress so slowly that it is unlikely to cause symptoms or affect the patient's health, sometimes the best approach may be to pursue active surveillance (formerly known as "watchful waiting") and not initiate any disease-directed treatment right away. The most common example is in the treatment of prostate cancer.

The American Cancer Society provides a list of questions cancer survivors should ask when choosing among recommended treatments. A link to this list is available at cancer.org/Treatment.

In cases of advanced cancer where prognosis is poor and effective curative treatment may not be available, the goal is to provide comfort and quality of life through the end of life for the patient and during bereavement for loved ones. In those circum-

stances, conversations among the patient, family, and clinicians about goals of care, advanced care planning, and hospice can be very helpful. Preferably, this conversation starts before the patient is too ill to participate.

Barriers to Treatment and Cancer Disparities

Quality of cancer care can significantly affect the likelihood of survival and the quality of life during and after cancer treatment. However, state-of-the-art cancer treatments are neither equitably accessible nor available across all segments of the population. As a result, disparities in cancer treatment and outcomes persist for medically underserved populations such as racial and ethnic minority groups, persons who are uninsured or underinsured, those from rural communities, and the elderly.⁷⁸

The availability and quality of cancer care may be influenced by structural barriers, as well as provider and patient factors.⁷⁹ Structural barriers include inadequate health insurance, complexities of the health care system, treatment facility hours of operation and appointment wait times, and access to transportation. Physician factors may include attitudes, beliefs, preferences, and biases that influence treatment delivery and recommendations. Patient decision making may be influenced by attitudes and beliefs about specific treatments, life circumstances and competing priorities, health literacy, and perceptions about the health care system. The relative influence of structural, provider, and patient factors is not well understood; however, there is consistent evidence that inadequate health insurance is an important barrier to receiving timely and appropriate care.⁸⁰

Even when patients have private or government health insurance, out-of-pocket costs of cancer care often pose a significant financial burden for them and their families. In 2008-2010, average annual health care expenses for newly diagnosed cancer patients younger than 65 years of age were \$21,222, with \$1,463 paid directly by survivors.⁸¹ In comparison, average annual health care expenses and out-of-pocket expenses for individuals with no history of cancer were \$3,450 and \$590, respectively. Estimated out-of-pocket costs were higher for the 65-and-older population than for the younger population.⁸¹

Costs for cancer patients who have no health insurance at the time of diagnosis vary by state and type of treatment facility, and may be based in part on income. Facilities that accept a substantial responsibility of serving the uninsured, such as "safety net" hospitals or those run by religious orders, typically only require patients to pay an amount they can realistically afford. The remainder of the cost is covered by donations, government funding, or other sources. Many states currently allow newly diagnosed cancer patients to enroll in Medicaid if they meet income guidelines after taking into account treatment costs and other state-specific eligibility requirements, such as requiring the patient to be disabled.

The implementation of the Affordable Care Act (ACA) may help alleviate the burden of cancer care for patients and families. The ACA provides new options for individuals with low incomes to obtain health insurance coverage, such as through the Health Insurance Marketplace or via expanded eligibility for Medicaid coverage. However, many states have chosen not to expand Medicaid coverage under the ACA at this time, so it will be important to monitor and assess the effects of the ACA on health care access and disparities.⁸²

Common Side Effects of Cancer and Its Treatment

The management of symptoms related to cancer and its treatment is an important part of cancer care, affecting the completion of treatment and both short-term and long-term quality of life, as well as physical and psychological functioning. Late effects may surface months or even years after treatment has ended. The most common side effects are pain, fatigue, and emotional distress.⁸³ These and other side effects of chemotherapy and radiation are described in the sidebar on page 24.

Bone density loss

Many cancer treatments lead to a reduction in bone density, which is referred to as osteoporosis or in cases that are less severe, osteopenia.⁸⁴ Bone density loss is a common side effect in breast cancer patients with chemotherapy-induced ovarian failure or those treated with aromatase inhibitors and in prostate cancer patients who are treated with androgen deprivation therapy.⁸⁵ Osteoporosis increases the risk of fractures and is associated with poorer quality of life, particularly among older survivors.^{86,87} Bone mineral density scans can assess bone loss in cancer patients at high risk due to their treatments and other factors; however, a recent study suggested that these tests are underutilized.⁸⁸ Several drugs including bisphosphonates have been shown to reduce bone loss in breast and prostate cancer patients.⁸⁹ In clinical trials, the monoclonal antibody denosumab has also been shown to increase bone density in some patients.^{90,91}

Cardiotoxicity (Heart damage)

Cancer treatment can cause a wide range of heart problems.⁹² A number of chemotherapy drugs, particularly anthracyclines, can cause cardiomyopathy (heart muscle damage), which sometimes can eventually result in heart failure.⁹³ The combination of the monoclonal antibody trastuzumab with anthracyclines appears to increase the risk of heart damage.^{94,95} Some monoclonal antibodies have also been associated with increased risk of high blood pressure.^{92,96} Radiation therapy to the chest has been linked to heart diseases, including accelerated atherosclerosis (blockage) of coronary arteries in the irradiated areas, dysrhythmia, and valvular disease.⁹⁷ Risk of heart disease increases in proportion to the amount of radiation received and persists for

at least 20 years.^{98,99} A long-term study of childhood cancer survivors found that the risk of cardiac death was 4 times higher for high-dose anthracycline chemotherapy recipients and 12 or more times higher among patients treated with radiotherapy to the chest, depending on the dose.¹⁰⁰

Cognitive (mental) deficits

Cognitive deficits from cancer treatment, often referred to as “chemo brain,” may include problems with attention, concentration, memory, mental processing speed, and language. Studies report between 15% and 50% of cancer patients treated with chemotherapy experience mental impairments; however, these problems can also occur in those receiving radiation and surgery without chemotherapy.^{101,102} Patient-reported rates of mental impairment are higher than those measured objectively.¹⁰³ The assessment of brain function is complicated by both emotional trauma of the cancer diagnosis and treatment-related effects including fatigue, depression, and anxiety, which can also affect cognitive performance, as well as the declines in mental function that typically accompany age.¹⁰⁴ A recent meta-analysis of breast cancer patients concluded that chemotherapy was associated with small deficits in verbal and spatial abilities that may persist for 6 months or more.¹⁰⁵ The risk of cognitive impairment from chemotherapy increases with advanced age, lower pre-treatment IQ, and those with a genetic variant that is associated with Alzheimer’s disease.^{106,107}

Distress

Cancer-related distress has been defined as a multifactorial, unpleasant emotional experience that may interfere with the ability to cope effectively with cancer and its treatment.¹⁰⁸ Distress in cancer patients may be difficult to identify because the signs often overlap with the symptoms of disease and treatment (e.g., fatigue, changes in appetite, and sleep disruptions). Almost all cancer patients experience some level of distress, ranging from mild, which may be addressed by discussions with the treatment team, to more severe, which should be referred to appropriate supportive services (mental health, social work, and counseling). A recent meta-analysis found that 30% to 40% of cancer patients had diagnosable mood disorders.¹⁰⁹ Research has demonstrated a strong link between distress and physical functioning, and experts in cancer rehabilitation medicine have recommended dual screening for both distress and physical impairments.¹¹⁰ The early detection and treatment of distress can improve treatment adherence and patient-provider communication and decrease the risk of severe depression or anxiety.¹⁰⁸

Fatigue

Fatigue is the most common, persistent side effect of cancer treatment, reported by about one-third of cancer survivors, particularly among those treated with chemotherapy.¹¹¹⁻¹¹³

Compared with fatigue experienced by healthy individuals, cancer-related fatigue is more severe, more distressing, and less likely to be relieved with rest.¹¹⁴ For many patients, chronic fatigue persists long after treatment has ended.¹¹⁵ Studies have found that cancer-related fatigue is commonly associated with sleep disturbance, emotional distress, and pain.¹¹⁴ Cancer patients may experience fatigue due to anemia, which can be treated with blood transfusion or less often, drugs that stimulate red blood cell production by the bone marrow. Other causes of cancer-related fatigue include depression, chronic inflammation, and alterations in metabolism.^{115, 116} A variety of interventions are recommended for cancer patients experiencing fatigue. Studies have shown that exercise, especially moderate-intensity exercise, reduces cancer-related fatigue. Psychological interventions may also be beneficial.¹¹⁷⁻¹¹⁹

Fear of cancer recurrence

Fear of cancer recurrence is one of the chief concerns of post-treatment cancer survivors and may persist long after treatment ends.¹²⁰ For example, data from the American Cancer Society Studies of Cancer Survivors indicate that nearly 60% of 1-year cancer survivors reported moderate to severe concerns about disease recurrence.¹²¹ Fear of recurrence is elevated among younger survivors and can be greater for caregivers than survivors.¹²² Relaxation techniques may be helpful in alleviating these fears.¹²³

Infertility

Infertility can result from surgery, radiation therapy, or chemotherapy.¹²⁴ In particular, alkylating agent-based chemotherapy has a highly toxic effect on the ovaries that increases with dose and duration.¹²⁵ For younger survivors especially, the loss of fertility can be a life-changing effect of cancer. Some women go through months without menstrual cycles, but then have them return. Having menstrual periods does not mean a woman is fertile, however. If chemotherapy or pelvic radiation damages the egg supply, a woman may have trouble getting pregnant even if she is menstruating, and will probably experience permanent menopause at an earlier age than normal. Women in their late 30s or 40s are more likely to stop having menstrual cycles permanently after cancer treatment because their egg supply was less to begin with compared to younger women.¹²⁶ Uterine radiation is also associated with miscarriage, preterm labor, and low-birthweight infants.¹²⁷ Male infertility from cancer surgery or pelvic radiation therapy can result from anatomic changes, hormonal imbalances, or lower production and quality of sperm.^{128, 129} Options for fertility preservation include freezing or banking sperm, eggs, or embryos.

More information and resources about fertility preservation and family planning for cancer patients is available on the Web site myoncofertility.org.

Lymphedema

Lymphedema is swelling, most often affecting the arms or legs, that can cause problems in functioning, pain, and affect body image. Lymphedema results from damage to parts of the lymphatic system that impedes the flow of lymph fluid. It occurs most often among women treated for breast cancer (see page 6). Surgical treatment or radiation affecting lymph nodes in the pelvic area can cause lymphedema of the legs for men and women diagnosed with other types of cancer. Signs and symptoms include a feeling of heaviness or discomfort (but usually not pain), restricted range of motion, and swelling. It is important for lymphedema to be diagnosed as early as possible in order to optimize treatment and slow progression.¹² Some evidence suggests that certain exercises may reduce the risk or lessen the severity of this condition.^{11, 12}

Pain

Cancer patients may experience pain at the time of diagnosis, during the course of active treatment, or after treatment has ended, even if their cancer does not return. Although studies suggest that pain is frequently underassessed, underreported, and undertreated, a meta-analysis estimated the prevalence of pain to be 59% among patients in active treatment, 33% among survivors after treatment, and 64% among those with advanced/metastatic/terminal disease.¹³⁰ Cancer-related pain reduces quality of life and is associated with depression and poor functioning.^{131, 132} Both surgery and radiation therapy can cause nerve damage, resulting in chronic pain. Chemotherapy drugs, such as vincristine, platinum-based drugs, and the taxanes, can damage sensory nerve cells causing peripheral neuropathy (weakness, numbness and pain, most often in the hands and feet).¹³³ The extent of damage is dose-dependent and may take months or years to resolve. Clinical practice guidelines from both the World Health Organization and the National Comprehensive Cancer Network recommend pain assessment throughout the course of treatment and continuing care.^{134, 135} The Society also offers an online resource, *Cancer-Related Pain: A Guide for Patients and Caregivers*, which is available at cancer.org.

For more information on cancer-related pain, see *Cancer Facts & Figures 2007*, Special Section, available online at cancer.org/statistics.

Pulmonary (lung) dysfunction

Surgery for lung cancer is usually associated with dyspnea (labored breathing) and reduced lung functioning. This is a particular problem in patients with preexisting lung problems due to smoking. In addition, damage to the respiratory system from chemotherapy and radiation for many types of cancer may progress without symptoms before manifesting as shortness of breath or other breathing problems long after treatment has ended.^{136, 137}

Side Effects Associated with Chemotherapy and Radiation Treatment

Anemia – A common side effect of chemotherapy, anemia is a condition where the body has too little hemoglobin contained in red blood cells to carry oxygen to the rest of the body. It can cause the following symptoms: fatigue, dizziness, paleness, a tendency to feel cold, shortness of breath, weakness, and racing heart.

Appetite changes, eating problems, and weight loss – Chemotherapy can cause nausea, taste changes, or mouth and throat problems that may make it difficult to eat. Radiation to the head and neck or parts of the digestive system may lead to difficulty eating and digesting. Loss of appetite, as well as weight loss, may result directly from effects of the cancer on the body's metabolism. Appetite loss may also be related to other side effects, such as depression or fatigue.

Bleeding or clotting problems – Chemotherapy can affect the bone marrow's ability to make platelets that help stop bleeding. Patients without enough platelets (thrombocytopenia) may bleed or bruise more easily than usual, even from a minor injury. Severe thrombocytopenia can lead to a life-threatening hemorrhage, such as in the brain or gastrointestinal tract. Some targeted therapy drugs can increase the risk of bleeding as well as the risk of the formation of serious blood clots, such as strokes and clots that form in the veins of the legs (deep vein thrombosis).

Constipation – Some chemotherapy drugs and pain medications can cause constipation. Constipation may also result from changes in diet and/or activity level.

Diarrhea – Chemotherapy can cause diarrhea by affecting the cells lining the intestine. Radiation to the stomach, abdomen, or pelvis can also cause diarrhea.

Fatigue – Ranging from mild lethargy to feeling completely exhausted, fatigue is one of the most common side effects of cancer treatment. It is different from feeling tired after a long day and often does not get better with rest or sleep. Fatigue tends to be the worst at the end of a treatment cycle.

Hair changes – Chemotherapy can cause hair loss (alopecia) on all parts of the body, not just the scalp, whereas hair loss resulting from radiation is limited to the specific area of treatment. Not all chemotherapy drugs cause hair loss. For most patients hair grows back after treatment, but it may be thinner, darker, or a different texture than it was before treatment. Some targeted therapies can cause hair to change colors and may also cause facial hair to grow faster than usual, including longer, thicker eyelashes.

Immune suppression – Chemotherapy and radiation therapy can suppress or weaken the immune system by lowering the number and/or effectiveness of white blood cells (especially neutrophils) and other immune system cells. A weakened immune system results in an increased risk of infection.

Infertility – For men, chemotherapy can reduce the number and quality of sperm, which may result in short- or long-term infertility. Chemotherapy can also cause infertility in women. Whether this happens and how long it lasts depends on many factors, including the type of drug, the doses given, and the age of the patient. Radiation to the pelvis can also affect fertility.

Memory and thinking problems – Chemotherapy and radiation to the brain can affect the cognitive (thinking) functions of the brain, including concentration, memory, comprehension, and reasoning. These changes are often subtle.

Mouth, gum, and throat problems – Chemotherapy and radiation to the head and neck can cause painful sores in the mouth and throat. It can make these areas dry and irritated or cause the sores to bleed. This can interfere with the intake of food and even liquids, leading to malnutrition and dehydration. Mouth sores are not only painful, but there is also concern of infection that may spread to other parts of the body. Some chemotherapy drugs can also cause short-term problems with the nerves in the throat, which can lead to pain with swallowing, especially food or liquids of extreme temperature.

Nausea and vomiting – These symptoms may start during chemotherapy treatment and last a few hours. Less often, severe nausea and vomiting can last for a few days. Some people getting chemotherapy feel queasy even before treatment begins; this conditioned response is called anticipatory nausea and is linked to poorly controlled nausea in previous treatment cycles. Radiation to certain regions of the body can also cause nausea or vomiting.

Nerve and muscle problems – Certain chemotherapy drugs can cause peripheral neuropathy, a potentially serious nerve problem that causes tingling, pins and needles, burning sensations, weakness, and/or numbness in the hands and feet.

Sexual problems – Chemotherapy and radiation to the pelvis can result in loss of libido, erectile dysfunction, and vaginal dryness and narrowing (leading to painful intercourse), and vaginal infections. Some sexual side effects can remain after treatment.

Shortness of breath (dyspnea) – Radiation to the chest and certain chemotherapy drugs can damage the lungs, causing shortness of breath. It may also occur as a result of chemotherapy-induced anemia.

Skin changes – Some chemotherapy and targeted therapy drugs may cause skin problems, including color changes, redness, itching, peeling, dryness, rashes, and acne. Some drugs can cause redness and pain of the palms and soles, which can worsen to blistering, peeling, and open sores, known as hand-foot syndrome. Some drugs make skin more sensitive to the sun. Most chemotherapy-related skin problems go away, but a few require immediate attention. Certain drugs can cause long-term tissue damage if they leak out of an IV. Symptoms of an allergic reaction, including sudden or severe itching, rash, or hives, should be reported right away. Radiation may cause skin to become red, irritated, and swollen, worsening to become blistered, peeling, or developing open sores. As radiation damage heals, the skin in treatment areas may appear tanned. After a few weeks, skin may become dry, flaky, itchy, or peel. Most skin reactions to radiation slowly go away after treatment; however, skin in the treatment area may remain darker than it was before.

Urine changes and bladder and kidney problems – Some chemotherapy drugs can irritate the bladder or cause kidney damage. They may also cause the urine to change color (orange, red, green, or yellow) or have a strong or medicine-like odor. Radiation to the pelvis can also irritate the bladder and lead to painful or frequent urination, which can become a chronic problem.

Weight gain – Chemotherapy can cause some people to gain weight, which may be due to inactivity, electrolyte imbalances, fluid retention, or corticosteroids contained in the drug regimen.

Sexual dysfunction

Sexual problems after cancer treatment affect survivors of many different cancers, including breast, bladder, colorectal, prostate, and gynecological.^{131, 138-140} Treatments that have a high rate of sexual side effects include surgery or radiation to the pelvic area, high-dose chemotherapy, aromatase inhibitors in women, and hormone therapies in men.¹⁴⁰ After the completion of treatment, 20% to 30% of breast cancer survivors¹⁴¹ and nearly 80% of prostate cancer survivors¹⁴² report sexual difficulties. Most sexual problems are caused by physical damage to nerves and blood vessels or hormonal changes that result in the loss of sexual desire, erection problems in men, and vaginal dryness and pain during sex in women. These sexual problems can be severe and tend not to be resolved unless specific treatments, including medical therapies and counseling, are provided. For people in a relationship, including the partner in treatment is crucial.¹⁴³

Impairment-driven Cancer Rehabilitation

Physical and mental impairments may significantly reduce survivors' ability to function, resulting in disability and poor quality of life. There are hundreds of different impairments that survivors may develop due to preexisting medical problems, the cancer itself, or cancer treatment. Examples of these include muscular weakness or paralysis, swallowing or speech problems, lymphedema, rotator cuff impingement, and physical disability as a result of major surgery. It is important to identify preexisting problems shortly after diagnosis and identify worsening or new issues all along the care continuum.¹¹⁰

Although general exercise and behavioral interventions are important and contribute to the overall health and well-being of survivors, they should not be confused with impairment-driven cancer rehabilitation that focuses on the diagnosis and treatment of specific cognitive and physical problems that are best addressed by qualified rehabilitation health care professionals such as physiatrists (doctors that specialize in rehabilitation medicine) and physical, occupational, and speech therapists. It is very common for survivors to have multiple impairments, and these should be treated with an interdisciplinary rehabilitation approach.

Palliative Care

Palliative or supportive care can provide better quality of life for cancer patients and their families by focusing on relieving the pain, stress, and other symptoms associated with cancer and its treatment. Palliative care is appropriate at any stage of cancer diagnosis and can be provided continuously alongside curative treatment.

Oncologists may provide palliative care as part of cancer treatment, or may request assistance from a specialized palliative care team. The palliative care team may include specially

trained doctors, nurses, chaplains/spiritual counselors, and social workers. Pharmacists, nutritionists, massage therapists, and others may also be part of the team. Palliative care is provided in a variety of settings, including hospitals and community cancer centers where patients and survivors frequently receive cancer care, and may also be available in long-term care facilities, through hospice, and even in the home.

Palliative care has been consistently shown to improve quality of life by addressing the harmful effects of pain, other physical symptoms, and emotional distress.¹⁴⁴ It has also been shown to improve survival in some cancer patients and reduce family caregiver burden.^{145, 146}

Palliative care is a rapidly growing medical specialty, but unfortunately these services are not yet available to all who need them. The American Cancer Society's nonprofit, nonpolitical advocacy affiliate, the American Cancer Society Cancer Action NetworkSM (ACS CAN), is working to improve access to palliative care for all adults and children facing cancer and other serious illnesses. For more information, visit acscan.org/qualityoflife and patientqualityoflife.org.

To learn more about palliative care or find palliative care professionals, visit the American Cancer Society Web site (cancer.org/treatment/treatmentsandsideeffects/palliativecare) and also getpalliativecare.org.

The Recovery Phase

After primary, curative treatment ends, most cancer patients transition to the recovery phase of survivorship. Challenges during this time may include difficulty returning to former roles such as parent or employee, anxiety about paying medical bills for cancer treatment, or decisions about which provider to see for the various health care needs that arise. Family and friends who went out of their way to provide support during treatment typically return to more normal levels of engagement and support, and the frequency of meetings with the cancer care team generally declines. These issues can make it difficult to smoothly negotiate the transition from treatment to recovery.

Regular medical care following primary treatment is particularly important for cancer survivors because of the potential lingering effects of treatment, as well as the risk of recurrence and additional cancer diagnoses. In 2006, the Institute of Medicine's (IOM) Committee on Cancer Survivorship published a report highlighting the need for a strategy to improve the coordination of ongoing care for survivors.¹⁴⁷ A follow-up report recommended that patients and their primary care providers be given a summary of their treatment and a comprehensive survivorship care plan developed by one or more members of the oncology team. The comprehensive treatment summary, which provides a foundation for the plan, contains the following personalized, detailed information:^{148, 149}

- Type of cancer, stage, and date of diagnosis
- Specific treatment and dates (e.g., names of surgical procedures, chemotherapy drug names and dosages, radiation dosages, etc.)
- Complications (side effects of treatment, hospitalizations, etc.)
- Supplemental therapy (e.g., physical therapy, adjuvant therapy, such as tamoxifen, etc.)

The survivorship care plan should be tailored to address each individual's specific needs. In addition to the treatment summary, the plan may include:

- A schedule of follow-up medical visits, tests, and cancer screenings, including who will perform them and where
- Symptoms that may be a sign of cancer recurrence
- Potential long-term treatment effects and their symptoms
- Behavior recommendations to promote a healthy recovery
- Community resources

Early studies have found that survivorship care plans help survivors feel more informed, make healthier diet and exercise choices, and increase the likelihood that patients will share this information with their health care team members.¹⁵⁰ Studies are also evaluating the short- and long-term benefits of survivorship care plans on health outcomes, health behaviors, and health care coordination.¹⁵¹

However, there are numerous obstacles to the implementation of survivorship care plans in the current health care system, such as lack of compensation for the time and effort to create the plan, shortage of time to develop and discuss the plan with the patient, and lack of clarity about who is responsible for their production.¹⁵² As a result, many survivors do not receive this information. A recent study found that only 20% of oncologists consistently provide survivorship care plans to their patients.¹⁵³ The implementation of survivorship care plans could be facilitated by the development of consensus guidelines for survivor care to provide content for the plans and the use of electronic systems to reduce the time required of clinicians to individually tailor the plans.¹⁵⁴

Long-term Survivorship

Long-term survivorship can be both stressful and hopeful. Survivors are relieved to have completed treatment, but may have to make physical, emotional, social, and spiritual adjustments to their lifestyle – in other words, to find a “new normal.” The following section includes common issues related to quality of life, risk of recurrence and subsequent cancers, and health behaviors of cancer survivors.

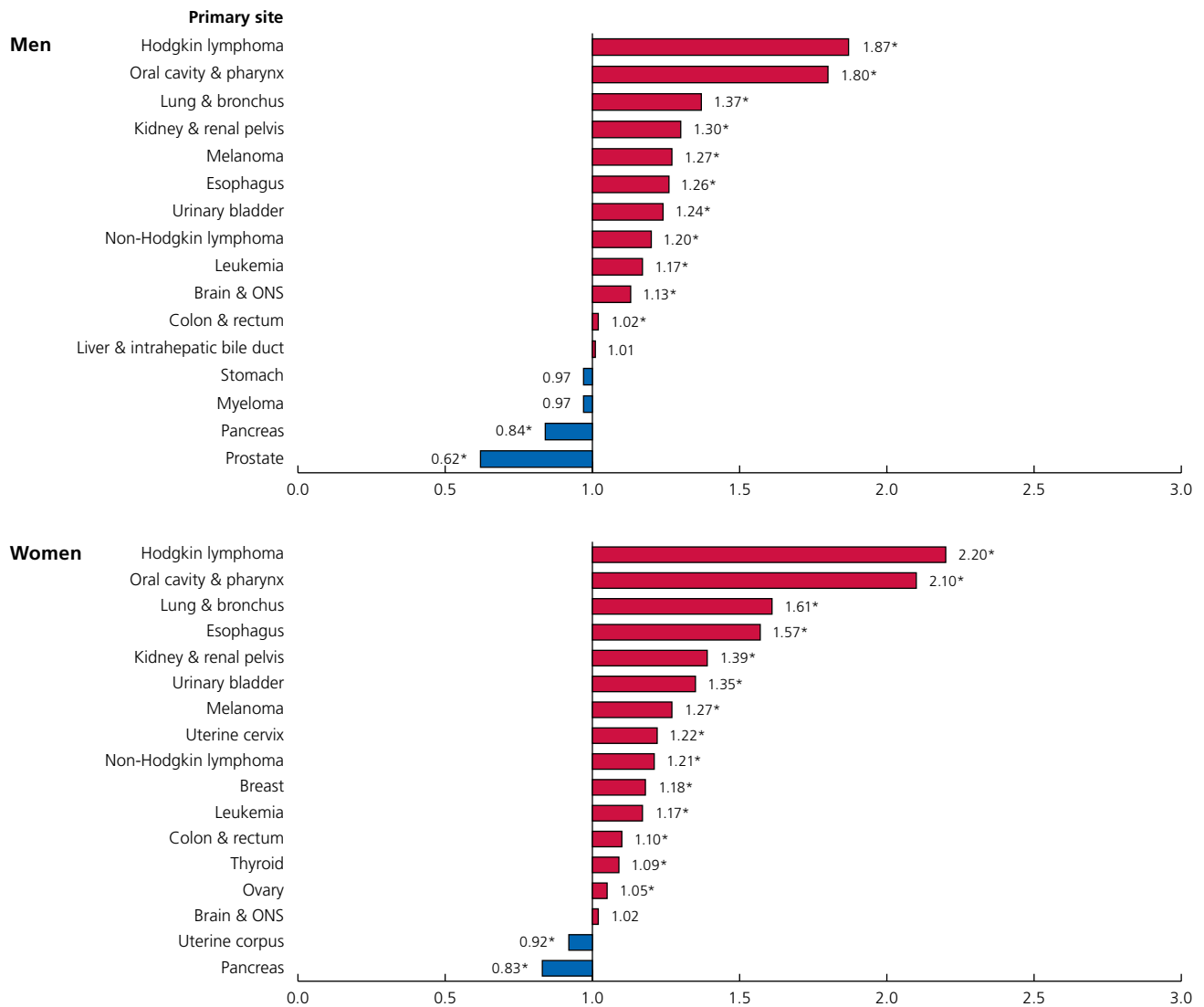
Quality of Life

Quality of life is a broad multidimensional concept that considers a person's physical, emotional, social, and spiritual well-being.¹⁵⁵ According to data from the National Health Interview Survey, approximately one in four cancer survivors has a decreased quality of life due to physical problems and one in 10 due to emotional problems.¹⁵⁶ Physical well-being is the degree to which symptoms and side effects, such as pain, fatigue, and poor sleep quality, affect the ability to perform normal daily activities. Emotional, or psychological, well-being refers to the ability to maintain control over anxiety, depression, fear of cancer recurrence, and problems with memory and concentration. Social well-being primarily addresses relationships with family members and friends, including intimacy and sexuality. Employment, insurance, and financial concerns also affect social well-being. Finally, spiritual well-being is derived from drawing meaning from the cancer experience, either in the context of religion or

through maintaining hope and resilience in the face of uncertainty about one's future health.

Although quality of life may decline considerably during and shortly after active cancer treatment, the majority of disease-free cancer survivors (5 years or more) report a quality of life comparable to those with no history of cancer.¹⁵⁷ Still, many survivors continue to suffer. Individuals who have a history of more invasive and aggressive treatments tend to report poorer functioning and quality of life in the long term. Certain groups, such as racial/ethnic minorities, those who were diagnosed at younger ages, and those with lower socioeconomic status, also report greater difficulty regaining quality of life.¹⁵⁸⁻¹⁶⁰ For example, one study of breast cancer survivors found that black women and women with lower socioeconomic status had poorer physical functioning than survivors of other race/ethnicities and with higher socioeconomic status.¹⁶¹ Age is also an important predictor of quality of life; survivors diagnosed at a younger age tend to have poorer emotional functioning, whereas older age at diagnosis is often associated with poorer physical functioning.^{162, 163} Many survivors of childhood cancer have cognitive or functional deficits that impact their ability to successfully complete their education and find employment, which in turn can impact psychological well-being and lower quality of life.¹⁹

Figure 16. Observed-to-expected (O/E) Ratios for Subsequent Cancers by Primary Site and Sex, Ages 20 and Older, 1973-2010



*p<0.05

Note: Observed-to-expected ratio is the number of cancers observed in a population of cancer survivors divided by the number of cancers expected. An O/E greater than 1 (red bar) indicates that the risk is greater than expected while an O/E less than 1 (blue bar) indicates reduced risk.

Source: Surveillance, Epidemiology, and End Results (SEER) Program, 18 SEER registries, 1973-2010, Division of Cancer Control and Population Sciences, National Cancer Institute.³³

American Cancer Society, Surveillance and Health Services Research, 2014

Risk of Recurrence and Subsequent Cancers

Cancer survivors are at risk for recurrence of the original cancer or the development of a second primary (new) cancer. Even after treatment of the original cancer appears to have been effective, cancer cells may persist in the body and eventually grow to the point where they are detected either near the site of the original cancer or elsewhere in the body. When this occurs, it is called a recurrence or metastasis. A second (or multiple) primary cancer is the occurrence of a new cancer that is biologically distinct from the original cancer. Whether a new cancer is a new primary

cancer or a recurrence of the original cancer is important because it determines staging procedures, prognosis, and treatment.

Although national estimates of recurrence are not available because data on recurrence are not collected by cancer registries, a large breast cancer study found that recurrence rates varied depending on tumor characteristics, stage of disease, and treatments received.¹⁶⁴ Scientists are studying genetic tests that may predict the likelihood that cancers such as breast, colon, and melanoma will recur. For some types of cancer, there are formulas that can help estimate the chance of recurrence. Prostate

cancer is one type of cancer for which recurrence projections can be made, based on stage and grade of the cancer, and other clinical information.¹⁶⁵

The risk of developing a subsequent cancer varies by the type of first cancer diagnosed (referred to as the first primary site), treatment received, and age at diagnosis. Similar to cancer in general, the risk of a second cancer increases with age. As a whole, cancer survivors have a small (15%) increased lifetime risk of developing a second primary cancer, though some have a much higher risk. Ratios of the observed-to-expected number of cancer cases (O/E) are used to describe the risk for a subsequent cancer diagnosis among cancer survivors. Figures 16 (page 27) and 17 provide O/E ratios by primary site for adult and childhood cancer survivors. Adult survivors of Hodgkin lymphoma and cancers related to tobacco use (cancer of the oral cavity and pharynx, lung and bronchus, kidney and renal pelvis, esophagus, and urinary bladder) have the highest risk of subsequent cancers (Figure 16, page 27). The risk of developing a subsequent cancer is higher for survivors of childhood cancer. Among those diagnosed before age 20, survivors of retinoblastoma, Ewing sarcoma, and Hodgkin lymphoma have the highest risk of developing a second cancer (Figure 17).

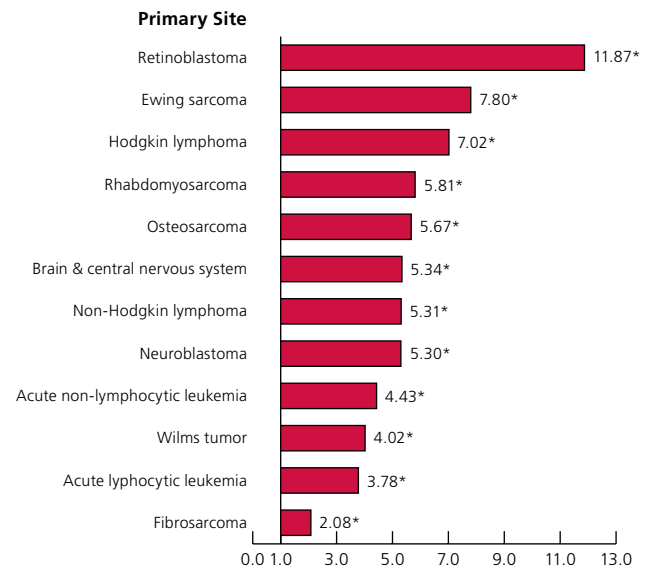
Other factors associated with developing more than one cancer include familial cancer syndromes and other genetic susceptibility factors, common exposures (e.g., tobacco), and the carcinogenic effects of cancer treatment.¹⁶⁴ For example, survivors of Hodgkin lymphoma have increased risk of additional cancers (e.g., breast cancer), largely as a result of radiation treatment; risk increases with higher radiation doses. Individuals with a tobacco-related cancer are at increased risk of developing an additional tobacco-related cancer. Avoiding tobacco use is the main strategy to reduce the burden of primary and secondary cancers related to tobacco. More information on health strategies to reduce the risk of recurrence and additional cancers is provided in the next section. For more information on multiple primary cancers, see *Cancer Facts & Figures 2009*, Special Section, available online at cancer.org/statistics.

Regaining and Improving Health through Healthy Behaviors

Healthy behaviors are especially important for survivors due to their increased risk for recurrence and developing a new cancer. For example, post-treatment physical activity has been associated with increased recurrence-free and overall survival, whereas overweight and obesity have been consistently associated with poorer survival for many cancers.¹⁶⁶⁻¹⁶⁹ Continued smoking after treatment increases the risk of recurrence and smoking-related second cancers.^{170, 171}

In addition to improving disease outcomes, healthy behaviors may also improve survivor functioning and quality of life.¹⁷²

Figure 17. Observed-to-expected (O/E) Ratios for Subsequent Cancers by Primary Site, Ages 0-19, 1973-2010



*p<0.05

Note: Observed-to-expected ratio is the number of cancers observed in a population of cancer survivors divided by the number of cancers expected.

Source: Surveillance Epidemiology, and End Results (SEER) Program, 18 SEER Registries, 1973-2010, Division of Cancer Control and Population Sciences, National Cancer Institute.³³

American Cancer Society, Surveillance and Health Services Research, 2014

Clinical trials demonstrate that exercise can improve heart and lung function and reduce cancer-related fatigue among survivors.^{173, 174} The growing evidence that primary preventive health behaviors are beneficial to survivors led the American Cancer Society to develop a guide for physical activity and nutrition during and after cancer treatment, the most recent version of which was published in April 2012.¹⁷⁵

Physical activity. In patients who are physically able, physical activity can hasten recovery from the immediate side effects of treatment and prevent long-term effects, and may reduce the risk of recurrence and increase survival.¹⁷³ In observational studies among breast cancer survivors, moderate physical activity has been associated with reduced risk of death from all causes (24-67%) and breast cancer (50-53%).¹⁷⁶ Similar benefits have been observed among colon cancer survivors.¹⁷⁷ Intervention studies have shown that exercise can improve fatigue, anxiety, depression, self-esteem, happiness, and quality of life in cancer survivors.¹⁷³

Exercise for cancer survivors should be individualized and tailored according to the disease site and stage and the survivor's capabilities. Barriers to engaging in physical activity may be symptomatic (e.g., fatigue, pain, and nausea), physical (e.g.,

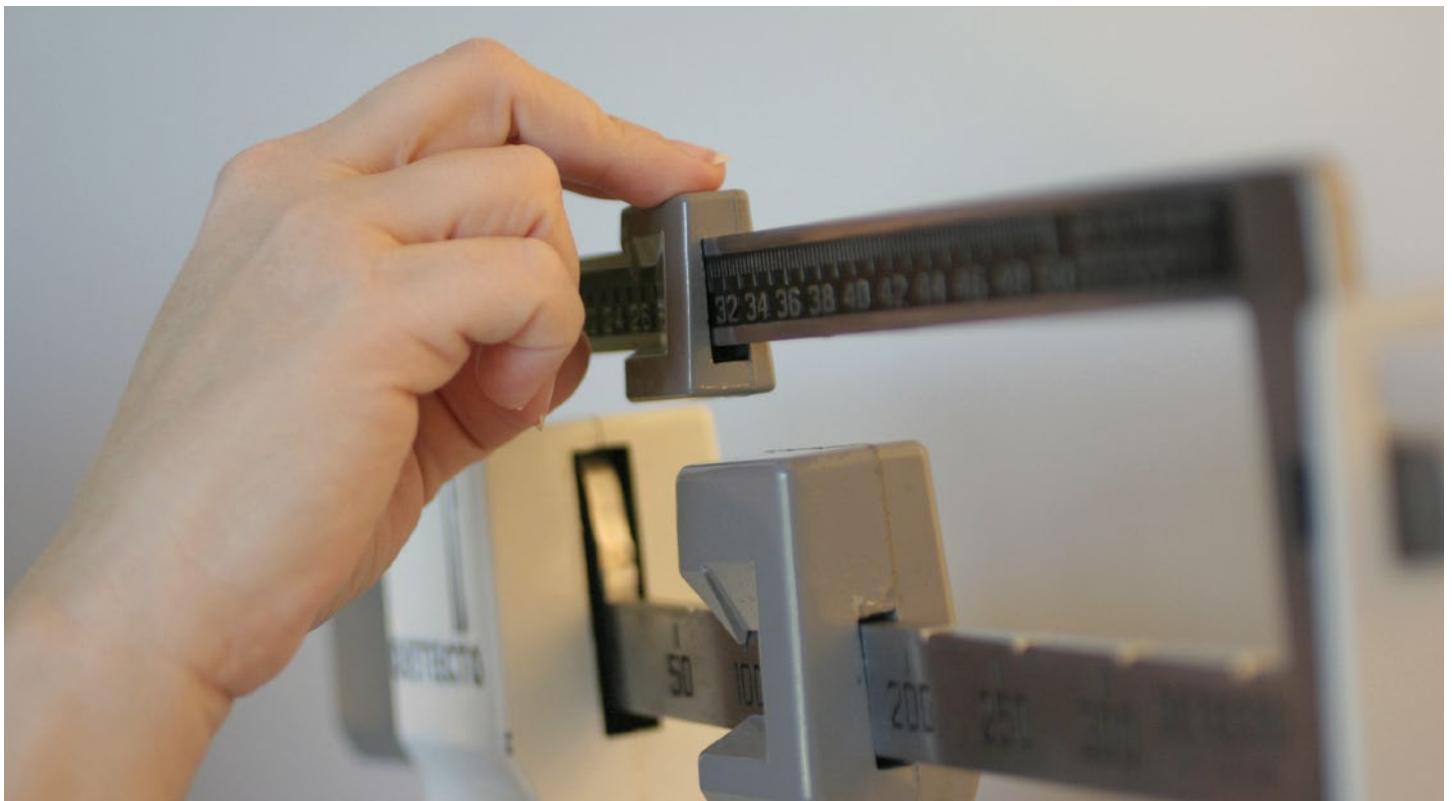
amputations, lymphedema, neuropathy), psychosocial (e.g., feelings of fear, lack of motivation, or hopelessness), or financial.¹⁷⁷ Physical impairments should be assessed by rehabilitation professionals prior to general exercise recommendations being implemented.¹¹⁰ Other barriers include lack of awareness of exercise programs, unfavorable community environments, and work and family obligations.

Nutrition and maintaining a healthy body weight. Weight management is an important issue for many survivors. Some patients begin the treatment process in a state of overweight or obesity and some may gain weight while in treatment, while others may become underweight due to treatment-related side effects (e.g., nausea, vomiting, difficulty swallowing).¹⁷⁸ Numerous studies have shown that obesity and weight gain in breast cancer survivors lead to a greater risk of recurrence and decreased survival; the evidence is less clear for colorectal and other cancers.¹⁷⁹ Obesity may also increase the risk of some treatment-related side effects, such as lymphedema and fatigue.¹⁸⁰

A diet that is plentiful in fruit, vegetables, and whole grains, but contains limited amounts of fat, red and processed meat, and simple sugars may reduce both the risk of developing second cancers and the risk of chronic diseases.¹⁸¹ In addition, alcohol consumption is an established cause of cancers of the mouth, pharynx, larynx, esophagus, liver, colorectum, and breast; therefore, the Society recommends that those who consume alcoholic beverages limit their consumption (2 drinks per day for men and 1 drink per day for women).¹⁷⁹

Smoking cessation. A significant number of cancer survivors continue to smoke after their diagnosis despite their increased risk for chronic health conditions and premature death. The majority of survivors who smoke were smokers before diagnosis.¹⁸² According to data from the National Health Interview Survey (2000-2008), 40% of cancer survivors ages 18 to 44 years were current smokers, compared to 24% of the general population.¹⁸² This information is troubling because of the known association between smoking and cancer development, the fact that survivors have a higher risk of developing second cancers, and because smoking interferes with some common treatments for cancer.¹⁸³ Studies have shown that smoking cessation efforts are most successful when they are initiated soon after diagnosis.¹⁸⁴ Cessation interventions tailored to cancer survivors are needed. For more information on Society resources for smoking cessation, see page 34.

Sun exposure. Cancer survivors should adopt skin care behaviors to decrease the risk of developing skin cancer, including: wearing sunscreen and protective clothing and avoiding sunbathing and artificial tanning. Skin cancer survivors are particularly susceptible to developing second skin cancers. In addition, survivors who have undergone radiation therapy are at an increased risk of skin cancer.¹⁸⁵



Concerns of Caregivers and Families

Cancer not only affects survivors but also their family members and close friends. As hospital space becomes limited to acute care and cancer treatments are delivered more frequently in outpatient settings, the tremendous responsibility of picking up where the health care team leaves off increasingly rests with the survivor's loved ones. It is estimated that there are nearly 4 million caregivers for adult cancer patients in the US.¹⁸⁶ Most caregivers are the spouse (66%) or offspring (18%) of cancer patients, and women (65%) are more likely to be caregivers than men.¹⁸⁷

Caregiver responsibilities can include gathering information to advise treatment decisions, attending to treatment side effects, coordinating medical care, managing financial issues, and providing emotional support to the survivor. One study found that even more than a year after the cancer diagnosis, caregivers were still spending an average of 8 hours a day providing care, with the highest time costs associated with providing care for lung cancer patients (Figure 18).¹⁸⁸

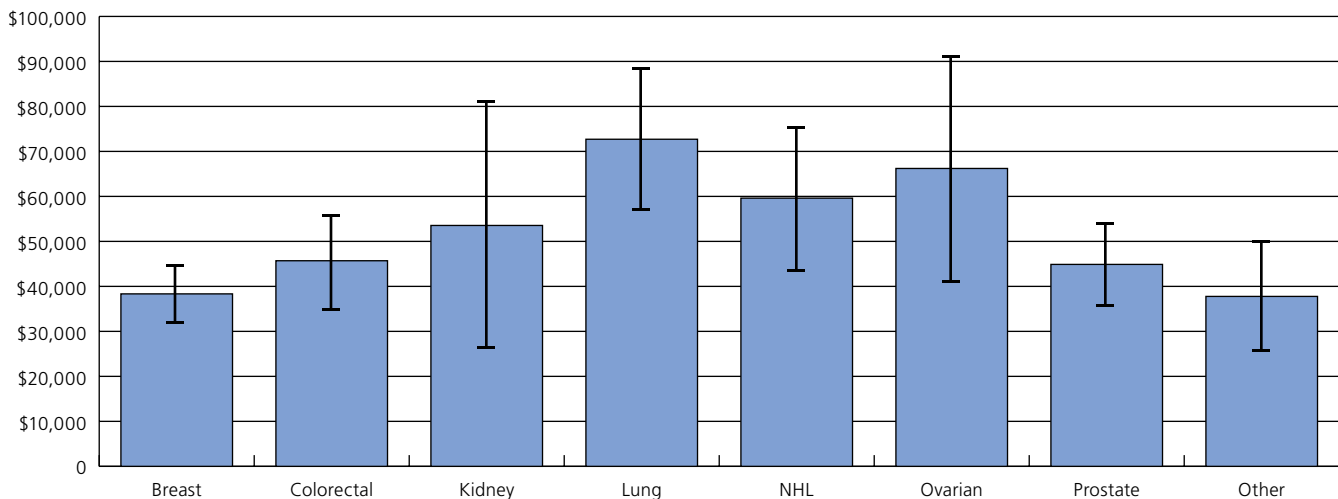
Caregivers may feel unprepared and overwhelmed in their new role, which can result in deterioration of their mental and physical health and a decline in quality of life.¹⁸⁹ Caregivers are increasingly vulnerable to psychological distress, depression, and anxiety, which can be exacerbated by feelings of social isolation. How the caregiver copes with these feelings can play a crucial role in their well-being.¹⁹⁰ Social support can help buffer the negative consequences of caregiver stress and can serve to

maintain, protect, or improve health. Caregivers fare better when they participate in social support programs aimed at teaching effective coping skills.¹⁹¹⁻¹⁹³ Consultation with palliative care teams has also been shown to help ease family caregiver burdens (see page 25 for more information on palliative care). A recent systematic review suggested that caregivers benefit most from problem-solving and communication skills interventions.¹⁹¹ Overall, interventions that are structured, goal-oriented, and integrate multiple aspects of care may be most helpful.¹⁹² Newer Web-based interventions have also shown promising results in reducing caregiver burden and improving mood.¹⁹³

A cancer diagnosis is often seen as a “teachable moment” for both survivors and caregivers, wherein the illness experience becomes a catalyst for behavior change and sustainable lifestyle benefits.¹⁹⁴ Increasing evidence has shown that caregivers may also be motivated to make positive changes to improve their own health after a loved one's cancer diagnosis.¹⁹⁵ It is within the “teachable moment” that health behavior interventions can become ingrained habits and have the greatest potential for long-term success throughout the cancer continuum for both survivors and caregivers.

Learning how to deal with the uncertainty about the future and worrying about whether the cancer will return are lingering issues for caregivers.¹⁹⁶ Not surprisingly, a higher level of fear of recurrence is usually experienced by caregivers of survivors

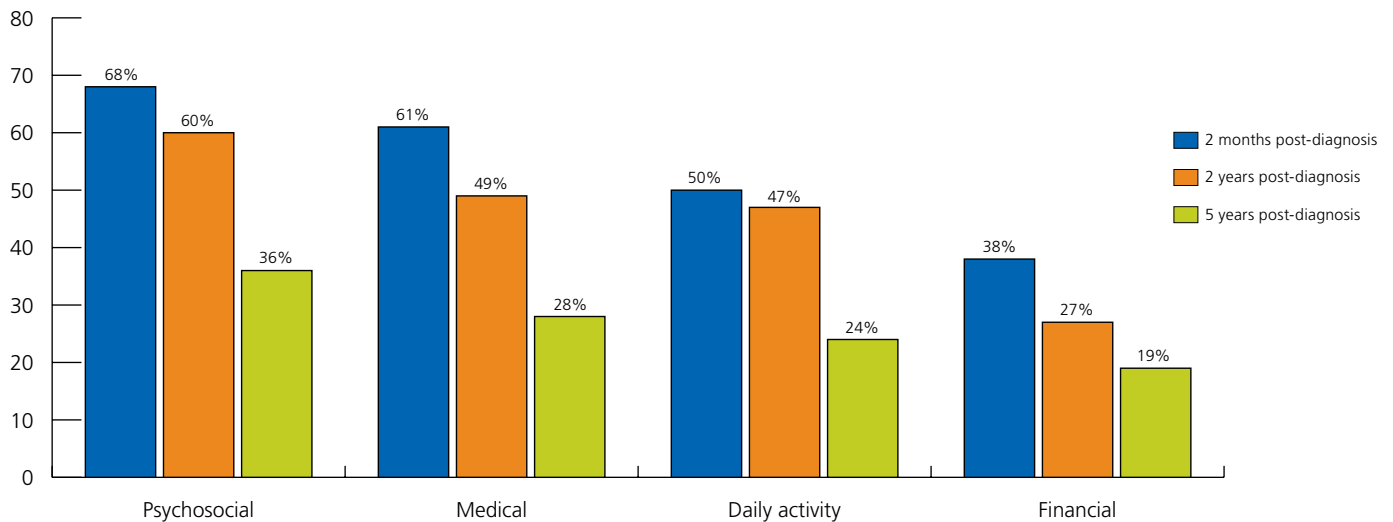
Figure 18. Monetary Value of Caregiver Time in the Two Years Following Diagnosis by Cancer Type



NHL: Non-Hodgkin lymphoma. Other: melanoma of the skin, and cancers of the bladder and uterus. Bars represent cost estimates, and lines represent 95% confidence intervals.

Source: Yabroff and Kim.¹⁸⁸ Reprinted from *Cancer* 2009;115(18 suppl):4362-4373. This material is reproduced with the permission of John Wiley & Sons, Inc.

Figure 19. Caregivers' Unmet Needs across the Cancer Trajectory



Source: Kim, et al.¹⁸⁷ Reprinted from *Psychooncology* 2010; 19(6):573-582. This material is reproduced with the permission of John Wiley & Sons, Inc.

diagnosed at a more advanced stage or with a more severe type of cancer.¹⁹⁷ With fewer oncology visits and a lack of consistent contact with health care providers, caregivers can be apprehensive as they reintegrate into life after treatment.¹⁹⁸

Caregivers report a variety of persistent unmet needs (Figure 19).¹⁹⁹ Caregivers' psychosocial needs are primarily centered on their ability to help the cancer survivor deal with their emotional distress and find meaning in the cancer experience. Ongoing medical needs include obtaining information about the cancer, its treatment, and side effects, and obtaining the best possible care for the survivor. Issues relating to caregivers' daily life, including their ability to balance their own personal care with the demands of caregiving, seem to be the most affected within two years of diagnosis.

Although cancer caregiving can be physically and emotionally demanding, it can also be a meaningful and satisfying experience. The phenomenon of finding good from difficult life experiences is known as benefit-finding or post-traumatic growth. Encountering a serious disease like cancer can prompt individuals to reprioritize life to better align with values, restore personal relationships, adopt a more positive self-view, and become more empathetic toward others. Recent studies have shown that both survivors and their caregivers often find benefit in the challenges associated with cancer.^{200, 201} Better adjustment and overall quality of life have been attributed to such positive growth. The cancer survivor's family members and friends become co-survivors in the cancer journey. Ensuring that caregivers are healthy, both emotionally and physically, is imperative for optimal survivorship care.



The American Cancer Society

How the American Cancer Society Saves Lives

The American Cancer Society is working relentlessly to save lives from cancer by helping people stay well and get well, by finding cures, and by fighting back against the disease.

Helping People Stay Well and Get Well

The American Cancer Society provides information that empowers people to take steps that help them prevent cancer or find it early, when it is most treatable. In addition, the Society helps eliminate barriers to cancer care through a number of high-profile programs. Among the most notable are the Road To Recovery® program (provides transportation to and from cancer treatments), the Hope Lodge® program (provides temporary housing for patients and families receiving treatment away from home), and the Patient Navigator Program (aids patients, families, and caregivers in navigating the cancer treatment process).

The Society also funds intramural and extramural research and training grants to help save more lives, prevent suffering, and address disparities in cancer care. Understanding that conquering cancer is as much a matter of public policy as scientific discovery, the Society's nonprofit, nonpartisan advocacy affiliate, the American Cancer Society Cancer Action Network (ACS CAN), strives to eliminate cancer disparities and enhance quality cancer care through policy and public health programs at the federal and state levels.

Cancer Information

Information, 24 hours a day, 7 days a week. The American Cancer Society is available 24 hours a day, seven days a week online at cancer.org and by calling 1-800-227-2345. Callers are connected with a Cancer Information Specialist who can help them locate a hospital, understand cancer and treatment options, learn what to expect and how to plan, help address insurance concerns, find financial resources, find a local support group, and more. The Society can also help people who speak languages other than English or Spanish find the assistance they need, offering services in 170 languages in total.

Information on every aspect of the cancer experience, from prevention through survivorship, is also available through the Society's Web site, cancer.org. The site includes an interactive cancer resource center containing in-depth information on every major cancer type.

The Society also publishes a wide variety of pamphlets and books that cover a multitude of topics, from patient education, quality of life, and caregiving issues to healthy living. A complete list of Society books for order is available at cancer.org/bookstore.

In addition, the Society publishes a variety of information sources for health care providers, including three clinical journals: *Cancer*, *Cancer Cytopathology*, and *CA: A Cancer Journal for Clinicians*. More information about free subscriptions and online access to *CA* and *Cancer Cytopathology* articles is available at cancer.org/journals. The Society also collaborates with numerous community groups, nationwide health organizations, and large employers to deliver health information and encourage Americans to adopt healthy lifestyle habits through the Society's science-based worksite programs.

Programs and Services

Day-to-day help and emotional support. The American Cancer Society can help cancer patients and their families find the resources they need to make decisions about the day-to-day challenges that can come from a cancer diagnosis, such as transportation to and from treatment, financial and insurance needs, and lodging when having to travel away from home for treatment. The Society also connects people with others who have been through similar experiences to offer emotional support.

Help with the health care system. Learning how to navigate the cancer journey and the health care system can be overwhelming for anyone, but it is particularly difficult for those who are medically underserved, those who experience language or health literacy barriers, or those with limited resources. The American Cancer Society Patient Navigator Program was designed to reach those most in need. As the largest oncology-focused patient navigator program in the country, the Society has specially trained patient navigators at 125 cancer treatment facilities across the nation. Patient navigators work in cooperation with patients, family members, caregivers, and staff of these facilities to connect patients with information, resources, and support to decrease barriers and ultimately to improve health outcomes. In 2013, more than 77,000 people relied on the Patient Navigator Program to help them through their diagnosis and treatment. The Society collaborates with a variety of organizations, including the National Cancer Institute's Center to Reduce Cancer Health Disparities, the Center for Medicare and Medicaid Services, numerous cancer treatment centers, and others to implement and evaluate this program.

Transportation to treatment. Cancer patients cite transportation to and from treatment as a critical need, second only to direct financial assistance. The American Cancer Society Road To Recovery program matches these patients with specially trained volunteer drivers. This program offers patients an additional key benefit of companionship and moral support during

National Cancer Survivorship Resource Center

The National Cancer Survivorship Resource Center (The Survivorship Center) is a collaboration between the American Cancer Society and the George Washington Cancer Institute, funded by the Centers for Disease Control and Prevention. Its goal is to shape the future of post-treatment cancer survivorship care and to improve the quality of life of cancer survivors. The Survivorship Center staff and more than 100 volunteer survivorship experts nationwide developed the tools listed below for cancer survivors, caregivers, health care professionals, and policy and advocacy efforts.

Tools for cancer survivors and caregivers

Life After Treatment Guide – a quick, easy-to-read information guide to help cancer survivors and their caregivers understand the various aspects of the survivorship journey. The guide also includes trusted resources for survivorship information and encourages communication with health care professionals. The guide is available online at cancer.org/survivorshipguide.

Survivorship Information Resource Inventory – an inventory of information resources to assist post-treatment survivors, available online at cancer.org/survivorshipresourceinventory

Tools for health care professionals

Prescription for Cancer Information – a tool to help health care professionals talk to survivors about resources available in their office or clinic, in the community, online, and over the telephone. This tool is available online at cancer.org/survivorshipprescription.

Moving Beyond Patient Satisfaction: Tips to Measure Program Impact Guide – a brief guide detailing indicators and outcome measures that can be used to monitor the success of survivorship programs, available online at cancer.org/survivorshipprogramevaluation

Clinical Care Follow-up Guidelines – are being developed to assist primary care providers as they provide long-term, follow-up care for cancer survivors. The guidelines will emphasize the importance of surveillance for cancer recurrence, address the assessment of long-term and late effects, and highlight the importance of healthy behaviors. Guidelines for prostate cancer survivors are expected to be released in 2014. An overview of this ongoing work was previously published.²⁰²

Cancer Survivorship E-Learning Series – a free continuing education program designed to provide information on how to tailor care to cancer survivors, and how to teach primary care providers the skills they need to provide follow-up care for cancer survivors. To find out more, log onto CancerSurvivorshipCenterEducation.org

Tools for advocates and policy makers

The Survivorship Center recognizes the importance of policies that support quality survivorship care. To educate policy makers on these issues, a white paper was created describing the priority areas for improving survivorship care. This paper is available online at cancer.org/survivorshippolicypaper.

To find out more about The Survivorship Center's activities, visit cancer.org/survivorshipcenter.

the drive to medical appointments. In 2012, the American Cancer Society provided more than 1.48 million transportation services to more than 81,000 constituents.

Lodging during treatment. When someone diagnosed with cancer must travel away from home for the best treatment, where to stay and how to afford accommodations are immediate concerns that sometimes affect treatment decisions. American Cancer Society Hope Lodge facilities provide free, homelike, temporary lodging for patients and their caregivers close to treatment centers, thereby easing the emotional and financial burden of finding affordable lodging. In 2013, the 31 Hope Lodge locations provided more than 265,000 nights of free lodging to nearly 43,000 patients and caregivers – saving them an estimated \$38 million in lodging expenses. In addition, the Society is partnering with the Extended Stay America hotel chain to offer free and reduced-rate housing to cancer patients throughout the US that cannot be accommodated at a Hope Lodge facility.

After treatment. The transition from active treatment to recovery can often create new questions for cancer survivors and their families. The American Cancer Society can help by providing information on many common concerns, such as post-treatment side effects, risk of recurrence, screening and early detection, and nutrition and physical activity, as well as helping provide emotional support through its support programs. The Society has established a collaborative effort with National Cancer Survivorship Resource Center to address the needs of post-treatment cancer survivors. Survivorship Care Plans give cancer survivors an overview of the care they have received and prioritizes areas for follow-up as they transition from a continuous care setting to recovery at home. The Society provides links to tools to help create survivorship care plans (cancer.org/survivorshipcareplans).

Breast cancer support. Through the American Cancer Society Reach To Recovery® program, trained breast cancer survivor vol-

unteers provide one-on-one support, information, and resource referrals to people facing breast cancer. Patients are matched with a volunteer who has had a similar breast cancer experience as well as other similar characteristics. These volunteers will meet one-on-one, either in person, by telephone, or via email, with women anytime throughout their breast cancer experience.

Cancer education classes. People with cancer and their caregivers need help coping with the challenges of living with the disease. The I Can Cope® initiative is a free online educational program for people facing cancer and their families and friends. The program is comprised of short, self-paced classes that can be taken at any time. Many topics are offered, such as information about cancer, managing treatments and side effects, healthy eating during and after treatment, communicating with family and friends, finding resources, and more. These free classes are available anytime at cancer.org/icancope.

Hair-loss and mastectomy products. Some women wear wigs, hats, breast forms, and bras to help cope with the effects of mastectomy and hair loss. The American Cancer Society “*tlc*” *Tender Loving Care*®, magazine/catalog offers informative articles and a line of products to help women who are battling cancer restore their appearance and self-esteem. “*tlc*” products and catalogs may be ordered online at tlcdirect.org or by calling 1-800-850-9445. All proceeds from product sales go back into the Society’s programs and services for patients and survivors.

Help with appearance-related side effects of treatment. The Look Good Feel Better® program is a collaboration of the American Cancer Society, the Personal Care Products Council Foundation, and the Professional Beauty Association that helps women learn beauty techniques to restore their self-image and cope with appearance-related side effects of cancer treatment. This free program engages certified, licensed beauty professionals trained as Look Good Feel Better volunteers to provide tips on makeup, skin care, head coverings, and style. Information and materials are also available for men and teens. To learn more, visit the Look Good Feel Better Web site at lookgoodfeelbetter.org or call 1-800-395-LOOK (1-800-395-5665).

Finding hope and inspiration. People with cancer and their loved ones do not have to face their cancer experience alone. They can connect with others who have “been there” on the American Cancer Society Cancer Survivors Network® program at csn.cancer.org. This dynamic online community was created by and for cancer survivors and their families to provide a welcoming and safe place to support one another, share their experiences, and exchange practical tips. The American Cancer Society Circle Of Sharing™ program (circleofsharing.cancer.org) allows users to share reliable medical information and resources with their trusted circle of caregivers, family, and friends for a more holistic approach to managing their disease.

Smoking cessation. The Society helps people quit tobacco through the American Cancer Society Quit For Life® Program, managed and operated by Alere Wellbeing. The phone-based coaching and Web-based learning support service has helped more than 1 million tobacco users. Information about this program is available at quitnow.net. A link to additional information on smoking cessation is available on the Society Web site, located at cancer.org/healthy.

Other Sources of Survivor Information and Support

CancerCare

1-800-813-HOPE or 1-800-813-4673

cancercare.org

Professionally facilitated support services to anyone affected by cancer, including a toll-free counseling line, various support groups (online, telephone, or face-to-face), and Connect Education Workshops

Cancer Support Community

1-888-793-9355

cancersupportcommunity.org

Support services available through a network of professionally led, community-based centers, hospitals, community oncology practices, and online. Focused on providing essential, but often overlooked, services including support groups, counseling, education, and healthy lifestyle programs. In collaboration with the LIVESTRONG Foundation, the Cancer Support Community developed the Cancer Transitions program for post-treatment cancer survivors, which covers the benefits of exercise, nutrition, emotional support, and medical management.

Family Caregiver Alliance

1-800-445-8106

caregiver.org

The Family Caregiver Alliance (FCA) is a public voice for caregivers, illuminating the daily challenges they face, offering them the assistance they so desperately need and deserve, and championing their cause through education, services, research, and advocacy. The FCA established the National Center on Caregiving (NCC) to advance the development of high-quality, cost-effective programs and policies for caregivers in every state in the country. The NCC sponsors the Family Care Navigator to help caregivers locate support services in their communities.

LIVESTRONG Foundation

1-855-220-7777

livestrong.org

The LIVESTRONG Foundation fights to improve the lives of people affected by cancer now. Created in 1997, the foundation provides free services and resources that improve patient and survivor outcomes and address the practical, emotional, employment and financial challenges that come with cancer.

National Coalition for Cancer Survivorship
1-877-NCCS-YES or 1-877-622-7937
canceradvocacy.org

National Coalition for Cancer Survivorship (NCCS) offers free publications and resources that empower people to become strong advocates for their own care or the care of others. The coalition's flagship program is the award-winning Cancer Survival Toolbox, a self-learning audio series developed by leading cancer organizations to help people develop crucial skills to understand and meet the challenges of their illness.

Patient Advocate Foundation
1-800-532-5274 (English), 1-800-516-9256 (Spanish)
patientadvocate.org

The Patient Advocate Foundation (PAF) is a national nonprofit organization that seeks to safeguard patients through effective mediation, assuring access to care, maintenance of employment, and preservation of financial stability. PAF serves as an active liaison between patients and their insurer, employer, and/or creditors to resolve insurance, job retention, and/or debt crisis matters relative to their diagnosis through professional case managers, doctors, and health care attorneys.

Finding Cures

Research is at the heart of the American Cancer Society's mission. For more than 65 years, the Society has been finding answers that save lives – from changes in lifestyle to new approaches in therapies to improving cancer patients' quality of life. No single private, not-for-profit organization in the US has invested more to find the causes and cures of cancer than the American Cancer Society. We relentlessly pursue the answers that help us understand how to prevent, detect, and treat all cancer types. We combine the world's best and brightest researchers with the world's largest, oldest, and most effective community-based anti-cancer organization to put answers into action.

As of February 18, 2014, the Society is funding approximately \$64 million in cancer treatment research and more than \$98 million in cancer control, survivorship, and outcomes research. The Society has awarded 62 grants in symptom management, and palliative care focused on patient, survivor, and quality of life research. Of those, 34 grants were funded through a partnership with the National Palliative Care Research Center over the past seven years, with three new grantees added in 2013.

Specific examples of ongoing and recent intramural and extramural research include:

- Exploring physical and psychosocial adjustment to cancer and identifying factors affecting quality of life through the Society's ongoing nationwide studies of cancer survivors
- Identifying and prioritizing gaps in information and resources for cancer survivors as they transition from active treatment back to the community care setting

- Developing and implementing a process to measure the effective control of pain, other symptoms, and side effects for those who have been affected by cancer
- Examining differences in receipt of treatment by race/ethnicity and insurance status in the National Cancer Data Base
- Developing a gene expression tool to predict which children with medulloblastoma (a type of brain tumor) can be treated with chemotherapy alone and thus avoid the harmful effects of radiation to the brain
- Studying neurotoxic side effects of a commonly used chemotherapeutic agent in children to determine which symptoms during treatment are indicative of long-term deficits
- Evaluating a tool to help women with metastatic breast cancer make thoughtful treatment decisions in collaboration with their medical providers that are medically sound and aligned with their own values, priorities, and preferences
- Identifying the prevalence and risk factors for severe urinary adverse effects that occur after pelvic radiation
- Comparing the effectiveness of follow-up cancer survivorship care in childhood cancer patients randomized to either 1) a specialty survivor clinic or 2) a patient's primary care doctor empowered with care recommendations provided by a cancer survivor specialist
- Studying how men and their partners cope with sexual recovery after surgery for prostate cancer in order to develop strategies to support couples who want to restore intimacy after treatment

Fighting Back

Conquering cancer is as much a matter of public policy as scientific discovery. Whether it's advocating for quality, affordable health care for all Americans, increasing funding for cancer research and programs, or enacting laws and policies that help decrease tobacco use, lawmakers play a critical role in determining how much progress we make as a country to defeat cancer. The American Cancer Society Cancer Action Network (ACS CAN), the Society's nonprofit nonpartisan advocacy affiliate, uses applied policy analysis, direct lobbying, grassroots action, and media advocacy to ensure elected officials nationwide pass laws that help save lives from cancer.

Created in 2001, ACS CAN is the force behind a powerful grassroots movement uniting and empowering cancer patients, survivors, caregivers, and their families to fight back against cancer. The nation's leading voice advocating for public policies that are helping to defeat cancer, the organization works to encourage elected officials and candidates to make cancer a top national priority. In recent years, ACS CAN has worked to pass a number of laws at the federal, state, and local levels focused on preventing cancer and detecting it early, increasing research on ways to prevent and treat cancer, improving access to lifesaving screenings and treat-

ment, and improving quality of life for cancer patients. Some recent advocacy accomplishments impacting cancer patients include:

- Passage and implementation of the Affordable Care Act (ACA) of 2010, comprehensive legislation that:
 - Prohibits insurance companies from denying insurance coverage based on preexisting conditions
 - Prohibits insurance coverage from being rescinded when a patient gets sick
 - Removes lifetime and annual limits from all insurance plans
 - Allows children and young adults up to age 26 to be covered under their parents' insurance plans
 - Makes coverage for routine care costs available to patients who take part in clinical trials
 - Requires all new health insurance plans and Medicare to cover preventive services rated "A" or "B" by the US Preventive Services Task Force (USPTF) at no cost to patients (including breast, cervical, and colorectal cancer screening and smoking cessation treatment)
 - Provides a discount on brand and generic drugs for beneficiaries who fall in the Medicare Part D gap in coverage (i.e., the "doughnut hole")
 - Secures coverage for a new annual wellness visit with a personalized prevention plan for Medicare beneficiaries
 - Creates incentives for health care providers to deliver more coordinated and integrated care to beneficiaries enrolled in Medicare and Medicaid
 - Requires state Medicaid programs to provide pregnant women with tobacco cessation treatment at no cost
 - Protects children and families against state rules that limit program eligibility or increase premiums or enrollment fees in Medicaid
 - Provides funding to states that choose to expand Medicaid coverage to low-income adults (below 133% of the federal poverty level)
 - Establishes a National Institutes of Health Interagency Pain Research Advisory Committee to coordinate pain management research initiatives and an Institute of Medicine Pain Conference series that will be important to relieving cancer-related pain and other chronic pain conditions
 - Establishes a National Prevention and Health Promotion Strategy; a National Prevention, Health Promotion and Public Health Council; and a Prevention and Public Health Fund with mandatory funding to prioritize, coordinate, oversee, and fund prevention-related activities nationwide
 - Prioritizes health disparities at the National Institutes of Health, establishes a network of federal-specific offices of minority health, and creates an Office of Women's Health
- Enhances data collection and reporting to ensure racial and ethnic minorities are receiving appropriate, timely, and quality health care
- Authorizes grants to help states and local jurisdictions address health workforce needs
- Requires chain restaurants to provide calorie information on menus and have other nutrition information available to consumers upon request and requires chain vending machine owners or operators to display calorie information for all products available for sale
- Improving quality of life and reducing suffering by ensuring that patients and survivors receive high-quality cancer care that matches treatments to patient and family goals across their life course. The Society and ACS CAN have:
 - Advocated for balanced pain policies in multiple states and at the federal level to ensure patients and survivors have continued access to the treatments that promote better pain management and improved quality of life
 - Advanced a new quality-of-life legislative platform that addresses the needs for better patient access to palliative care services and calls for expanded research funding and increased health professions workforce to provide patients with serious illnesses better patient-centered, coordinated care
 - Increased public awareness of the increasingly urgent cancer drug shortage problem and advocated for solutions to the complex, multiple causes of cancer drug shortages

Together, ACS CAN and the American Cancer Society are taking action to move toward integrating palliative care in our nation's health care delivery system. The public policy goal is to provide patients greater access to palliative care at the point of diagnosis as an essential element of providing quality patient-centered care. The Society's targeted research programs and ACS CAN's associated advocacy initiatives include a specific focus on:

- Managing physical and psychosocial symptoms
- Reducing barriers to receiving care
- Increasing cancer knowledge and empowering patient and caregiver decision making and communications with treatment teams

Some efforts in the fight against cancer are more visible than others, but each successful battle is an important contribution to what will ultimately be victory over the disease. The Society, working together with ACS CAN and its grassroots movement, is making sure the voice of the cancer community is heard in the halls of government and is empowering communities everywhere to fight back. The Society is also rallying people to fight back against the disease through our Relay For Life® and Making Strides Against Breast Cancer® programs. The American Cancer

Society Relay For Life program is a life-changing event that gives everyone in communities across the globe a chance to celebrate the lives of people who have battled cancer, remember loved ones lost, and fight back against the disease, making it the world's largest movement to end cancer. At Relay events, teams of people camp out at a local high school, park, or fairground and take turns walking or running around track or path for up

to 24 hours. Making Strides Against Breast Cancer events unite more than 300 communities each year to finish the fight against breast cancer. Dollars raised fund groundbreaking research, provide free resources and support to help people throughout their cancer journey, and ensure access to mammograms for women who need them.

Sources of Statistics

Prevalence. Cancer prevalence (i.e., the number of cancer survivors) was projected using the Prevalence, Incidence Approach Model (PIAMOD), a method that calculates prevalence from cancer incidence, cancer survival, and all-cause mortality.²⁰³ Incidence and survival were modeled by cancer type, sex, and age group using malignant cancer cases diagnosed during 1975-2007 from the nine oldest registries in the Surveillance, Epidemiology, and End Results (SEER) program (2010 data submission). Survival was assumed to be constant from 2007 through 2024. Mortality data for 1969-2008 were obtained from the National Center for Health Statistics and projected mortality rates for 2009 to 2024 were obtained from the Berkeley Mortality cohort life tables. Population projections for 2008 to 2024 were obtained from the US Bureau of Census. For each site and sex combination, an adjustment was made to align the projected prevalence with more directly estimated prevalence in 2009.²⁰⁴ For more information on this method, please see publications by Mariotto et al.^{205, 206}

New cancer cases. The numbers of new US cancer cases in the US in 2014 were published previously.²⁰⁷ The estimates were calculated using a spatiotemporal model based on incidence data from 49 states and the District of Columbia for the years 1995-2010 that met the North American Association of Central Cancer Registries' (NAACCR) high-quality data standard for incidence. This method considers geographic variations in sociodemographic and lifestyle factors, medical settings, and cancer screening behaviors as predictors of incidence, and also accounts for expected delays in case reporting.

Survival. This report presents relative survival rates to describe cancer survival. Relative survival adjusts for normal life expectancy (and events such as death from heart disease, accidents, and diseases of old age) by comparing survival among cancer patients to that of people not diagnosed with cancer who are of the same age, race, and sex. Five-year survival statistics presented in this publication were originally published in the National Cancer Institute's *Cancer Statistics Review 1975-2010*.²⁵ Current survival estimates are based on cases diagnosed during 2003 to 2009 and followed through 2010 from the 18 SEER registries followed through 2010. However, when describing changes

in 5-year relative survival over time, survival rates were based on cases from the 9 SEER registries. In addition to 5-year relative survival rates, 1-year, 10-year, and 15-year survival rates are presented for selected cancer sites. These survival statistics are generated using the National Cancer Institute's SEER 18 database and SEER*Stat software version 8.0.4. One-year survival rates are based on cancer patients diagnosed from 2006 to 2009, 10-year survival rates are based on diagnoses from 1997 to 2009, and 15-year survival rates are based on diagnoses from 1992 to 2009; all patients were followed through 2010.

National Cancer Data Base. The National Cancer Data Base (NCDB) is a hospital-based cancer registry jointly sponsored by the American Cancer Society and the American College of Surgeons, and includes nearly 70% of all malignant cancers in the United States from more than 1,400 facilities accredited by the American College of Surgeons' Commission on Cancer (CoC).²⁰⁸ The NCDB contains standardized data regarding patient demographics and cancer type and histology and staging, as well as first course of treatment. Unlike population-based registries, the NCDB also collects chemotherapy treatment information. Some targeted therapies are classified as chemotherapy, thus data on chemotherapy use includes targeted therapy, as well as immunotherapy drugs. For further information regarding the classification of anti-cancer drugs into the categories of chemotherapy, immunotherapy, hormonal therapy, and targeted therapy, see the SEER-Rx Web site, seer.cancer.gov/tools/seerrx. Treatment data do not include diagnostic procedures.

Although the NCDB is a useful tool in describing cancer treatment at a national level, it may not be fully representative of all cancer patients treated in the United States. Data are only collected for patients diagnosed or treated at CoC-accredited facilities, which are more likely to be located in urban areas and tend to be larger centers compared to non-CoC accredited facilities.²⁰⁹ Additionally, cancers that are treated and diagnosed in non-hospital settings (e.g., melanoma, prostate cancer, and non-muscle invasive bladder cancer) are less likely to be captured by the NCDB because it is a hospital-based registry. More information on the NCDB can be found at their Web site, facs.org/cancer/ncdb.

SEER-Medicare Database. The SEER-Medicare linked database is a large integrated population-based cancer registry and claims dataset.²⁷ This database was accessed to supplement data not available in the NCDB such as data on use of specific chemotherapeutic agents. Clinical, demographic, and cause of death information for persons with cancer are included from the 18 SEER registries, covering approximately 26% of the US population. Medicare is the primary health insurer for 97% of the US

population 65 years of age and older. Medicare data includes inpatient, outpatient, physician services, home health, durable medical equipment and prescription drug claims files. The linkage of these two data sources is the collaborative effort of the NCI, the SEER registries, and the Centers for Medicare and Medicaid Services. More information on the SEER-Medicare database can be found at their Web site (appliedresearch.cancer.gov/seermedicare/).

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