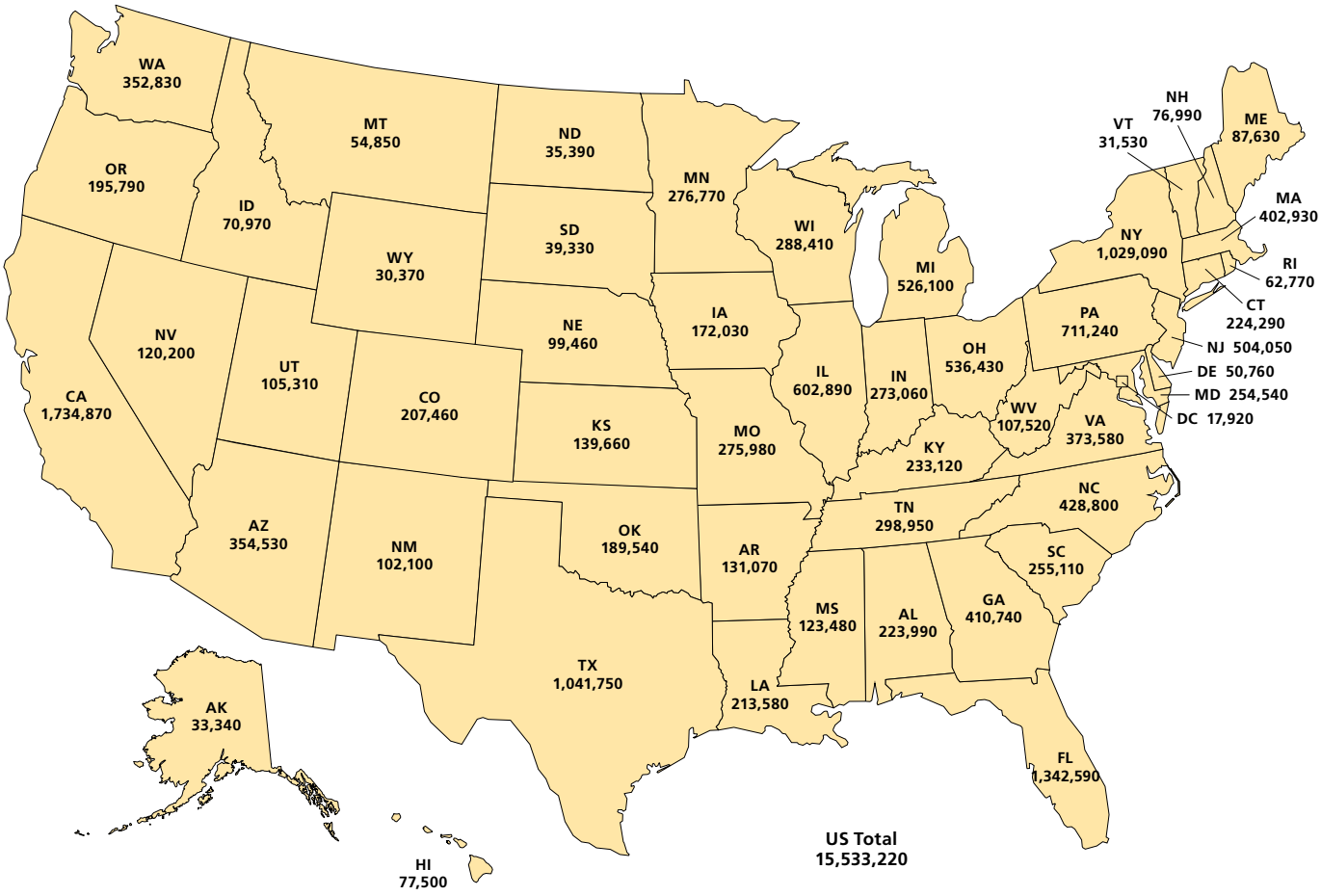
Cancer Treatment & Survivorship Facts & Figures 2016-2017

Estimated Numbers of Cancer Survivors by State as of January 1, 2016



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

American Cancer Society®

Contents

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This publication attempts to summarize current scientific information about cancer.
Except when specified, it does not represent the official policy of the American Cancer Society.

Suggested citation: American Cancer Society. *Cancer Treatment & Survivorship Facts & Figures 2016-2017.* Atlanta: American Cancer Society; 2016

Introduction

Who Are Cancer Survivors?

In this report, the term "cancer survivor" refers to any person with a history of cancer, from the time of diagnosis through the remainder of their life. Henceforth, the terms cancer patient and cancer survivor are used interchangeably without preference, although it is recognized that not all people with a cancer diagnosis identify with the term "cancer survivor."

There are at least three phases of cancer survival: the time from diagnosis to the end of initial treatment, the transition from treatment to extended survival, and long-term survival.[1] Survivorship encompasses a range of cancer experiences and trajectories, including:

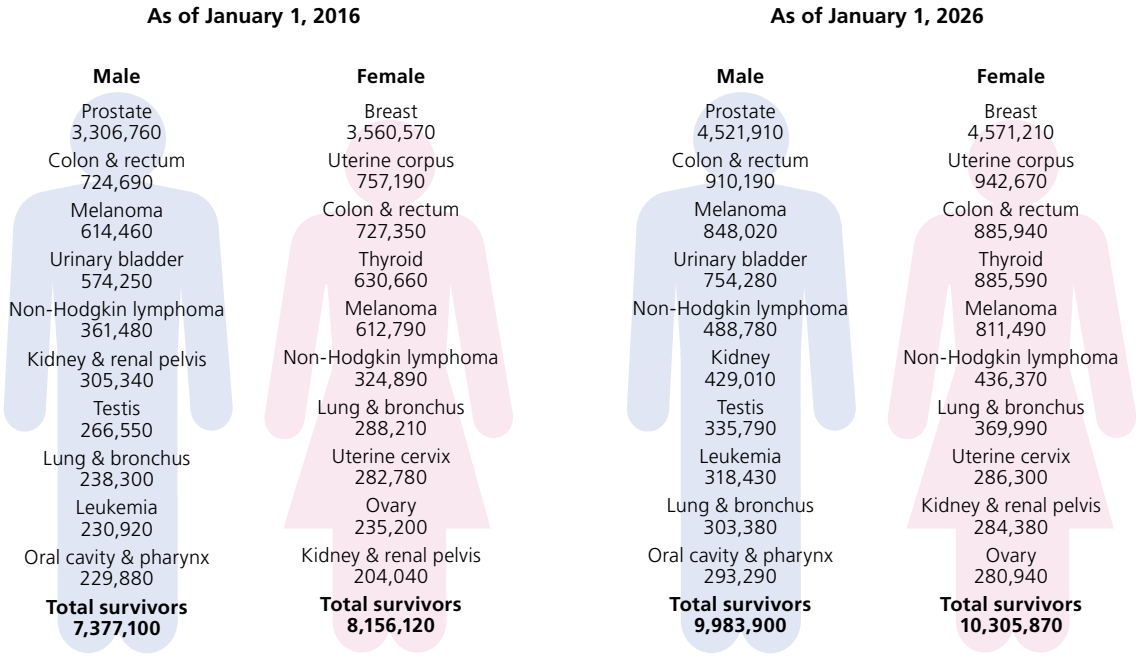
- Living cancer-free after treatment for the remainder of life
- Living cancer-free after treatment for many years but experiencing one or more serious, late complications of treatment
- Living cancer-free after treatment for many years, but dying after a late recurrence
- Living cancer-free after the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

The goals of treatment are to "cure" the cancer, if possible; 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 if the cancer is completely eradicated, for many patients, the initial course of therapy is successful and the cancer never returns. However, some 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.

How Many Cancer Survivors Are Alive in the US?

More than 15.5 million children and adults with a history of cancer were alive on January 1, 2016, in the United States. This estimate, also referred to as cancer prevalence, does not include carcinoma in situ (non-invasive cancer) of any site except urinary bladder, nor does it include basal cell or squamous cell skin

Figure 1. Estimated Numbers of US Cancer Survivors



NOTE: Beginning with the 2016-2017 edition, estimates for specific cancer types now take into account the potential for a history of more than one cancer type. Estimates should not be compared to those from previous years. See Sources of Statistics, page 34, for more information.

Source: Surveillance Research Program, Division of Cancer Control and Population Sciences, National Cancer Institute.

American Cancer Society, Surveillance and Health Services Research, 2016

cancers. The 10 most prevalent cancers represented among male and female survivors are shown in Figure 1, page 1. Cancers of the prostate and colon and rectum, and melanoma are the three most prevalent among males, whereas cancers of the breast, uterine corpus, and colon and rectum are most prevalent among females. It is important to note that the number of total survivors is fewer than the sum of all cancers combined because some people are diagnosed with more than one type of cancer.

The majority of cancer survivors (67%) were diagnosed 5 or more years ago, and 17% were diagnosed 20 or more years ago (Table 1). Nearly half (47%) of survivors are 70 years of age or older, while only 11% are younger than 50 (Table 2).

How Many Cancer Survivors Are Expected to Be Alive in the US in 2026?

By January 1, 2026, it is estimated that the population of cancer survivors will increase to 20.3 million: almost 10 million males and 10.3 million females (Figure 1, page 1).

How Is Cancer Treated?

There are many different types of cancer treatment, including surgery, radiation therapy, and/or systemic therapy (e.g., chemotherapy, hormonal therapy, immune therapy, and targeted therapy). Treatments may be used alone or in combination depending on the type and stage of cancer; tumor characteris-

Table 1. Estimated Number of US Cancer Survivors by Sex and Years Since Diagnosis as of January 1, 2016

	Male and Female			Male			Female		
Years since diagnosis	Number	Percent	Cumulative Percent	Number	Percent	Cumulative Percent	Number	Percent	Cumulative Percent
0 to <5 years	5,189,400	33%	33%	2,713,350	37%	37%	2,476,050	30%	30%
5 to <10 years	3,530,890	23%	56%	1,798,090	24%	61%	1,732,800	21%	52%
10 to <15 years	2,493,340	16%	72%	1,212,930	16%	78%	1,280,410	16%	67%
15 to <20 years	1,655,400	11%	83%	729,830	10%	87%	925,570	11%	79%
20 to <25 years	1,082,460	7%	90%	443,630	6%	94%	638,830	8%	86%
25 to <30 years	660,180	4%	94%	228,710	3%	97%	431,470	5%	92%
30+ years	921,550	6%	100%	250,560	3%	100%	670,990	8%	100%

Note: Percentages do not sum to 100% due to rounding.
Source: Surveillance Research Program, Division of Cancer Control and Population Sciences, National Cancer Institute.

Table 2. Estimated Number of US Cancer Survivors by Sex and Age at Prevalance as of January 1, 2016

	Male and Female			Male			Female		
	Number	Percent	Cumulative Percent	Number	Percent	Cumulative Percent	Number	Percent	Cumulative Percent
All ages	15,533,220			7,377,100			8,156,120		
0-14	65,190	<1%	<1%	32,060	<1%	<1%	33,130	<1%	<1%
15-19	47,180	<1%	1%	23,610	<1%	1%	23,570	<1%	1%
20-29	187,490	1%	2%	90,730	1%	2%	96,760	1%	2%
30-39	408,790	3%	5%	166,170	2%	4%	242,620	3%	5%
40-49	958,600	6%	11%	347,700	5%	9%	610,900	7%	12%
50-59	2,389,670	15%	26%	963,410	13%	22%	1,426,260	17%	30%
60-69	4,141,950	27%	53%	2,027,150	27%	49%	2,114,800	26%	56%
70-79	4,011,790	26%	79%	2,148,940	29%	79%	1,862,850	23%	79%
80+	3,322,560	21%	100%	1,577,330	21%	100%	1,745,230	21%	100%

Note: Percentages do not sum to 100% due to rounding.
Source: Surveillance Research Program, Division of Cancer Control and Population Sciences, National Cancer Institute.

tics; and the patient's age, health, and preferences. Supportive therapies to reduce side effects and address other patient and family quality of life concerns may also be used. When it is anticipated that a cancer will grow so slowly that it is unlikely to ever cause symptoms or affect the patient's health, the approach may be to avoid or defer immediate treatment and monitor the cancer over time to determine whether to start treatment at a later time (known as active surveillance). Active surveillance is most commonly used for prostate cancer.

Radiation therapy is the use of high-energy beams or particles to kill cancer cells, and may be delivered from a source outside the body (as in external beam radiation) or internally (e.g., brachytherapy). Systemic therapies are drugs that travel through the bloodstream, potentially affecting all parts of the body, and work using different mechanisms. For example, chemotherapy drugs generally attack cells that grow quickly, such as cancer cells. Hormonal therapy works by either blocking or decreasing the level of the body's natural hormones, which sometimes act to promote cancer growth. Targeted drugs are newer therapies that work by attacking specific molecules on cancer cells (or nearby cells) that normally help cancers grow.

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 quality of life, as well as physical and psychological functioning. Side effects may occur during active treatment, or months or even years later. The most common side effects are pain, fatigue, and emotional distress.[2-4] These and other effects of cancer treatment are described below. It is important to note that the severity of these effects varies from person to person and by treatment type, and improves over time for many patients. For more information on side effects of treatment for specific cancer types, see "Selected Cancers," page 6.

Anemia

Anemia is a condition in which a patient does not have an adequate number of red blood cells to carry oxygen throughout the body, causing fatigue, dizziness, paleness, a tendency to feel cold, shortness of breath, weakness, and a racing heart. It is a common side effect of chemotherapy and may be treated with careful monitoring, blood transfusions, or certain drugs.

Bleeding or clotting

Chemotherapy can reduce the body's ability to make platelets. 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. Some targeted therapy drugs can increase the risk of bleeding and serious blood clots.

Bone density loss

Many cancer treatments can lead to a reduction in bone density, which is referred to as osteoporosis, or in cases that are less severe, osteopenia.[5] Osteoporosis is commonly associated with hormone treatments for breast and prostate cancers and can also be seen in patients treated with steroids. Specific drugs are available to help prevent or reduce bone loss, but these therapies can also have side effects.

Bowel dysfunction

Chemotherapy can cause diarrhea by affecting the cells lining the intestine. Radiation to the abdomen or pelvis, as well as some gastrointestinal surgeries (e.g., for colorectal cancer), can also cause diarrhea. Constipation is a side effect of some chemotherapy drugs and pain medications, but may also result from changes in diet and/or activity level.

Distress

Cancer-related distress has been defined as a difficult, multifactorial experience that may interfere with the ability to cope effectively with cancer and its treatment.[6] Almost all cancer patients experience some level of distress, which should be referred to appropriate supportive services (mental health, social work, and counseling).[6, 7] 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). Distress may continue long after treatment; a recent study found that the prevalence of anxiety among long-term cancer survivors was elevated in comparison to the general population (18% versus 14%, respectively).[8] A number of effective interventions are available to help patients experiencing troubling levels of distress.[9]

Fatigue

Compared with fatigue experienced by healthy individuals, cancer-related fatigue is more severe, more distressing, and less likely to be relieved with rest.[10] 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.[11-13] Cancer patients may experience fatigue due to anemia, depression, chronic inflammation, and alterations in metabolism.[14, 15] A variety of interventions are recommended for cancer patients experiencing fatigue, such as moderate-intensity exercise.[10, 16]

Hair changes

Some chemotherapy drugs can cause hair loss on all parts of the body, whereas hair loss resulting from radiation is limited to the specific area of treatment. For most patients, hair grows back after treatment, but may be thinner, darker, or a different texture than it was before. Some targeted therapies can cause hair color changes and may also cause facial hair to grow faster than

usual. For information on specific American Cancer Society programs and services that help patients manage appearance-related side effects like hair loss, see page 31.

Heart damage

Cancer treatment can cause a wide range of heart problems.[17] A number of chemotherapy drugs, particularly anthracyclines, can cause heart damage, which may increase risk of heart failure over time.[18] Risk of heart disease increases in proportion to the amount of radiation received to the chest and persists for at least 20 years.[19-21] Risk and severity can be reduced through healthy lifestyle modifications (e.g., smoking cessation, healthy diet, and exercise).

Immune suppression

Chemotherapy and radiation therapy can suppress or weaken the immune system by lowering the number and/or effectiveness of white blood cells and other immune system cells. A weakened immune system results in an increased risk of infection. It is important for cancer patients to understand their risk for infection, reduce risk with good hygiene and a healthy diet, and report symptoms of infection, such as fever, sore throat, or nasal congestion, to their health care provider.

Infertility

Infertility can result from surgery, radiation therapy, or chemotherapy among both men and women.[22-24] Pelvic radiation among women is associated with miscarriage, preterm labor, and low-birthweight infants.[25] Options for fertility preservation include freezing and banking sperm, eggs, or embryos. Timely referral to a specialist in reproductive endocrinology and infertility is critical due to the rapid loss of ovarian reserve among premenopausal women treated with chemotherapy.[22] Ideally, referral for consultation to a fertility specialist should occur prior to the onset of treatment that might result in compromised reproductive health.[26] Visit **myoncofertility.org** for more information and resources about fertility preservation and family planning for cancer patients.

Lung dysfunction

Surgery for lung cancer may cause reduced lung function resulting in shortness of breath, especially among survivors with preexisting lung damage due to smoking. In addition, chemotherapy and radiation for many types of cancer can damage the lungs, which can cause breathing problems long after treatment has ended.[27, 28] Consideration of referral for pre-surgical 'prehabilitation' as well as post-surgery rehabilitation may help minimize or partially restore lung function compromised by cancer treatment.[29, 30]

Lymphedema

Lymphedema results from a buildup of fluid caused by damage to parts of the lymphatic system from surgery or radiation. It most often affects breast cancer survivors, but can also be a complication of treatment for other cancers in which lymph nodes were affected. Treatments are available to reduce symptoms in some patients, but the optimal approach for this condition is still debated.[31] Infections can worsen the symptoms of lymphedema, so good hygiene to reduce infection risk is important. Patients who develop lymphedema should be referred to a physical or occupational therapist or to a specialist trained in lymphedema management.

Memory and other mental deficits

In addition to memory problems, mental deficits from cancer treatment may include mild to moderate problems with attention, concentration, mental processing speed, and language.[32] Although sometimes referred to as "chemobrain," these problems may also occur in patients receiving radiation and surgery without chemotherapy, including those whose cancer does not involve the brain or central nervous system. Studies report up to 75% of cancer patients receiving chemotherapy experience mental impairments during treatment; for some patients, these problems persist months to years after completing chemotherapy.[32] Research on interventions to prevent and treat these side effects is ongoing.[33]

Nausea, weight changes, and dietary issues

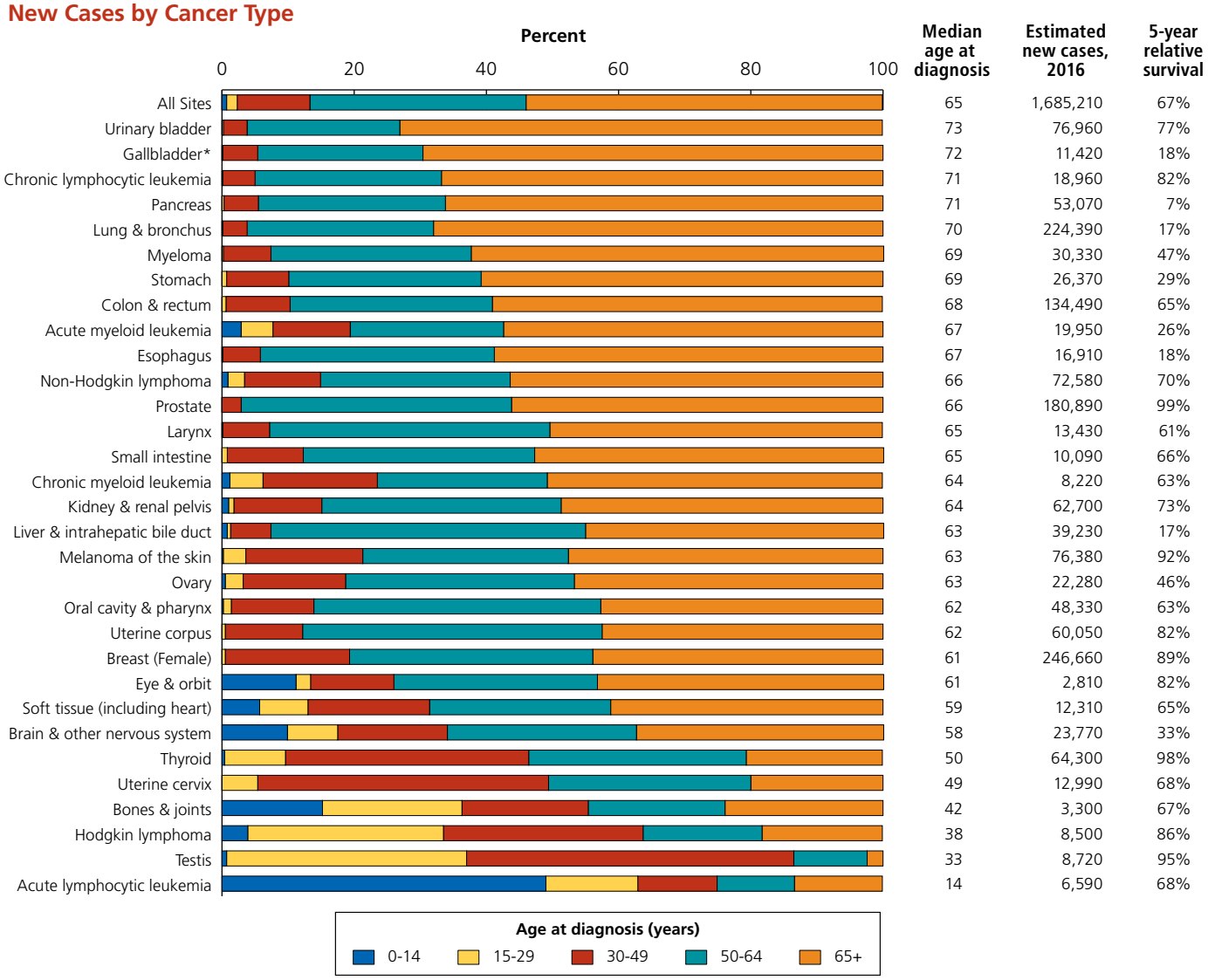
Chemotherapy can cause nausea, taste changes, or mouth and throat problems (e.g., sores, short-term nerve damage) that may make it difficult to eat. Radiation or surgery to the head and neck or parts of the digestive system may also lead to difficulty eating and digesting. In addition, loss of appetite, as well as weight loss, may result directly from effects of cancer on the body's metabolism. [34] Patients may be referred to a dietician for help with these symptoms. However, appetite loss may also be related to other side effects, such as depression or fatigue. Alternatively, chemotherapy and hormonal therapy can cause some people to gain weight, which may be due to inactivity, electrolyte imbalances, fluid retention, or steroids contained in the drug regimen.

Pain

Cancer patients may experience pain at the time of diagnosis, during active treatment, or after treatment has ended, even if their cancer does not return. Both surgery and radiation therapy can cause nerve damage that results in chronic pain. Some chemotherapy drugs can cause weakness, numbness, and pain, most often in the hands and feet.[35] Pain should be assessed throughout the course of treatment and continuing care.[36-38] Numerous strategies exist to minimize and manage pain, including pain medications, physical activity, and acupuncture.[37, 39, 40]

Visit **cancer.org** to see the Society's online resource *Cancer-Related Pain: A Guide for Patients and Caregivers.*

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



*New case estimate includes other biliary. Note: Cancer types are ranked in descending order of median age at diagnosis.
Sources: Age distribution based on 2011-2012 data from the North American Association of Central Cancer Registries and excludes incidence data from Arkansas and Nevada. Median age at diagnosis and 5-year relative survival are based on cases diagnosed during 2008-2012 and 2005-2011, respectively, from the 18 SEER registries and were previously published in the *SEER Cancer Statistics Review, 1975-2012*.[57] 2016 estimated cases from Cancer Statistics, 2016.[116]

American Cancer Society, Surveillance and Health Services Research, 2016

Sexual dysfunction

Sexual problems after cancer treatment affect survivors of many different cancers, including breast, bladder, colorectal, prostate, and gynecological.[41-44] Issues vary greatly in severity and tend not to be resolved unless specific treatments are provided, which may include medical therapies; non-hormonal, water-based lubricants and moisturizers; and psychoeducational support, group therapy, sexual counseling, marital counseling, or psychotherapy.[45]

Skin changes

Some chemotherapy and targeted therapy drugs may cause skin problems, including redness, blistering, itching, peeling, dryness, rashes, acne, and sensitivity to the sun. Some targeted therapy drugs can also cause an extensive rash over the face, neck, and chest. Most of these skin problems go away after treatment is finished, but 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, which might worsen to become blistered, peeling, or even open sores. Most skin reactions to radiation slowly go away after treatment, although skin may remain darker than it was before.

Urinary, 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 medicinal odor. Radiation to the pelvis can also irritate the bladder and lead to painful or frequent urination, which can become chronic.[46] Removal of the bladder (cystectomy) for muscle-invasive urinary bladder cancer requires urinary diversion through a "neobladder" or urostomy (see "Urinary Bladder," page 19 for more information).

Selected Cancers

This section contains information about treatment, survival, and common survivor concerns for the most prevalent cancer types. See the preceding section for more information on common side effects of cancer and its treatment.

Breast (Female)

It is estimated that there were more than 3.5 million women living in the US with a history of invasive breast cancer as of January 1, 2016, and an additional 246,660 women will be newly diagnosed in 2016. The median age at diagnosis is 61 (Figure 2, page 5). About 19% of breast cancers occur among women younger than age 50, and 44% occur in those older than 65. Mammography screening can help detect breast cancers at an early stage, when there are more treatment options and treatment is more likely to be successful.

Treatment and survival

Treatment for breast cancer usually involves breast-conserving surgery (BCS) (i.e., lumpectomy/partial mastectomy, in which only cancerous tissue plus a rim of normal tissue are removed) accompanied with radiation or mastectomy (surgical removal of the breast). When BCS is appropriately used for localized or regional cancers (followed with radiation to the breast), long-term survival is the same as treatment with mastectomy alone.[47, 48] However, some patients require mastectomy because of tumor characteristics, such as locally advanced stage, large or multiple tumors, or because they previously received radiation, are not able to be treated with radiation due to pre-existing medical conditions, or other obstacles (e.g., limited transportation to treatment).

BCS-eligible patients, however, are increasingly electing mastectomy for a variety of reasons, including reluctance to undergo radiation therapy or fear of recurrence.[49, 50] Younger women (those under 40 years of age) and patients with larger and/or more aggressive tumors are more likely to undergo mastectomy.[51] The number of women with early stage disease in one breast who undergo contralateral prophylactic mastectomy (CPM), or the removal of the unaffected breast, has also increased rapidly, from 5% of total mastectomies in 1998 to 30% in 2011.[49] Although CPM nearly eliminates the risk of developing a new

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. The two most common staging systems are described below, although some cancers (e.g., lymphoma) have alternative staging systems.

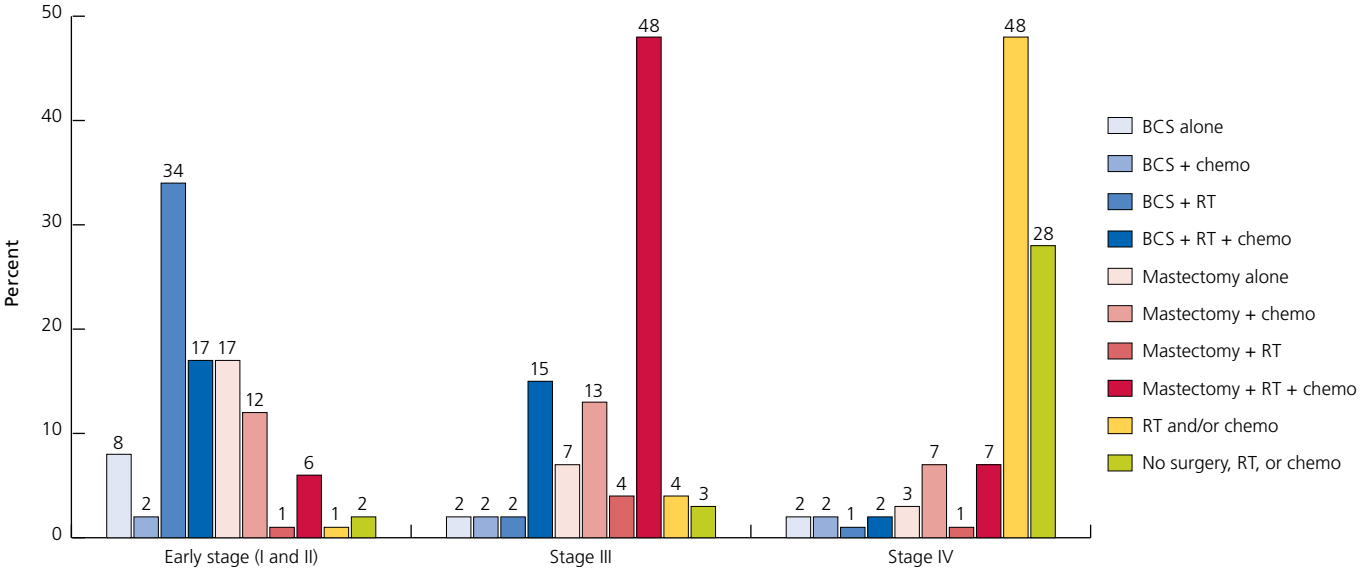
The TNM system, which is most often used by clinicians, assesses cancers in three ways: the size of the tumor (T) and/or whether it has grown to involve nearby areas, absence or presence of regional lymph node involvement (N), and absence or presence of distant metastases (M). Once the T, N, and M categories are determined, the tumor is assigned a stage of 0, I, II, III, or IV, with stage 0 referring to a noninvasive cancer that is limited to the layer of cells in which it originated, stage I being early stage invasive cancer, and stage IV being the most advanced stage.

A second and less complex staging system, called Summary Stage, has historically been used by population-based cancer registries. Cancers are classified as in situ, local, regional, or 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 distant 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 (population-based registries [e.g., Surveillance, Epidemiology, and End Results (SEER) program] versus hospital registries [i.e., National Cancer Data Base (NCDB)]). Although there are some exceptions (e.g., thyroid cancer for young patients), the TNM stage generally corresponds to Summary Stage 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 3. Female Breast Cancer Treatment Patterns (%) by Stage, 2013



BCS = breast-conserving surgery (lumpectomy/partial mastectomy, in which only cancerous tissue plus a rim of normal tissue are removed); chemo = chemotherapy and includes targeted therapy and immunotherapy drugs; mastectomy = surgical removal of the breast; RT = radiation therapy.

Source: National Cancer Data Base, 2013.[102]

American Cancer Society, Surveillance and Health Services Research, 2016

breast cancer, it does not improve long-term breast cancer survival for the majority of women and is associated with potential harms.[52-54]

Among women with early stage (I or II) breast cancer, 61% undergo BCS and 36% have a mastectomy (Figure 3). A much smaller percentage of women with stage III disease undergo BCS (21%), while 72% have mastectomy. Women with metastatic disease (stage IV) most often receive radiation and/or chemotherapy without surgery (48%), while 25% receive surgery alone or in combination with other treatments and 28% of patients receive no treatment.

Women who undergo mastectomy may elect to have breast reconstruction, either with a saline or silicone implant, tissue taken from elsewhere in the body, or a combination of the two. A recent large study found that 57% of women with early stage disease who received mastectomies underwent reconstructive procedures.[49] A woman considering breast reconstruction should discuss this option with her breast surgeon prior to mastectomy, as reconstruction options postmastectomy may be more limited.

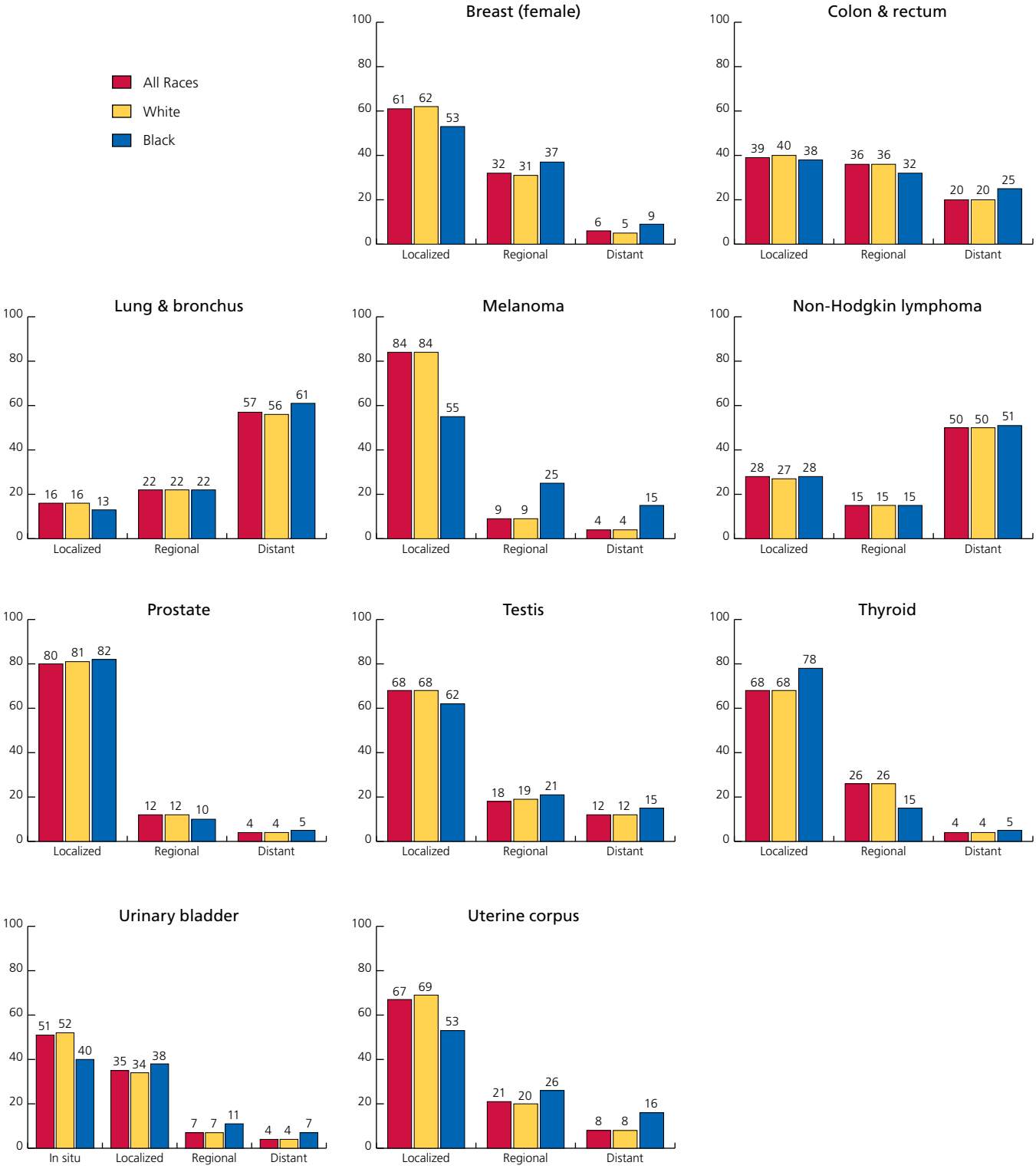
The benefit and timing of systemic therapy, which includes chemotherapy and hormonal and targeted therapy, is dependent on multiple factors, such as the size of the tumor, the number of lymph nodes involved, the presence of estrogen or progesterone hormone receptors on cancer cells (referred to as ER or PR positive tumors), and the amount of human epidermal growth factor receptor 2 (HER2) protein made by the cancer cells. Women whose breast cancer tests positive for hormone receptors (about 84% of cancers)[55] are candidates for treatment with hormonal therapy. Hormonal therapy is generally started after chemotherapy and radiation are complete (if they were needed). For premenopausal women, the standard hormonal treatment is tamoxifen for at least 5 years. For those who are postmenopausal, hormonal treatment may include tamoxifen and/or an aromatase inhibitor for 5 to 10 years.[56] Other hormonal therapy drugs are available for treatment of advanced disease.

All breast cancers should be tested for HER2 gene amplification or protein overexpression (about 14% of breast cancers)[55] because a number of drugs are available that target the HER2 receptor. Targeted therapies can be given as single agents or in combination with chemotherapy or hormonal therapy.

The 5-, 10-, and 15-year relative survival rates for female breast cancer are 89%, 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.) More than half (61%) of cases are diagnosed at a localized stage, for which the 5-year relative survival is 99% (Figure 4, page 8, and Figure 5, page 9). In addition to stage, cancer-related factors that influence survival include tumor grade, hormone receptor status, and HER2 status.

Female breast cancer survival rates have increased over time due to widespread mammography use and improvements in treatment.[57,58] However, compared to white women, black women

Figure 4. Stage Distribution (%) by Race and Cancer Type, 2005-2011



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

Source: Howlader, et al, 2015.[57]

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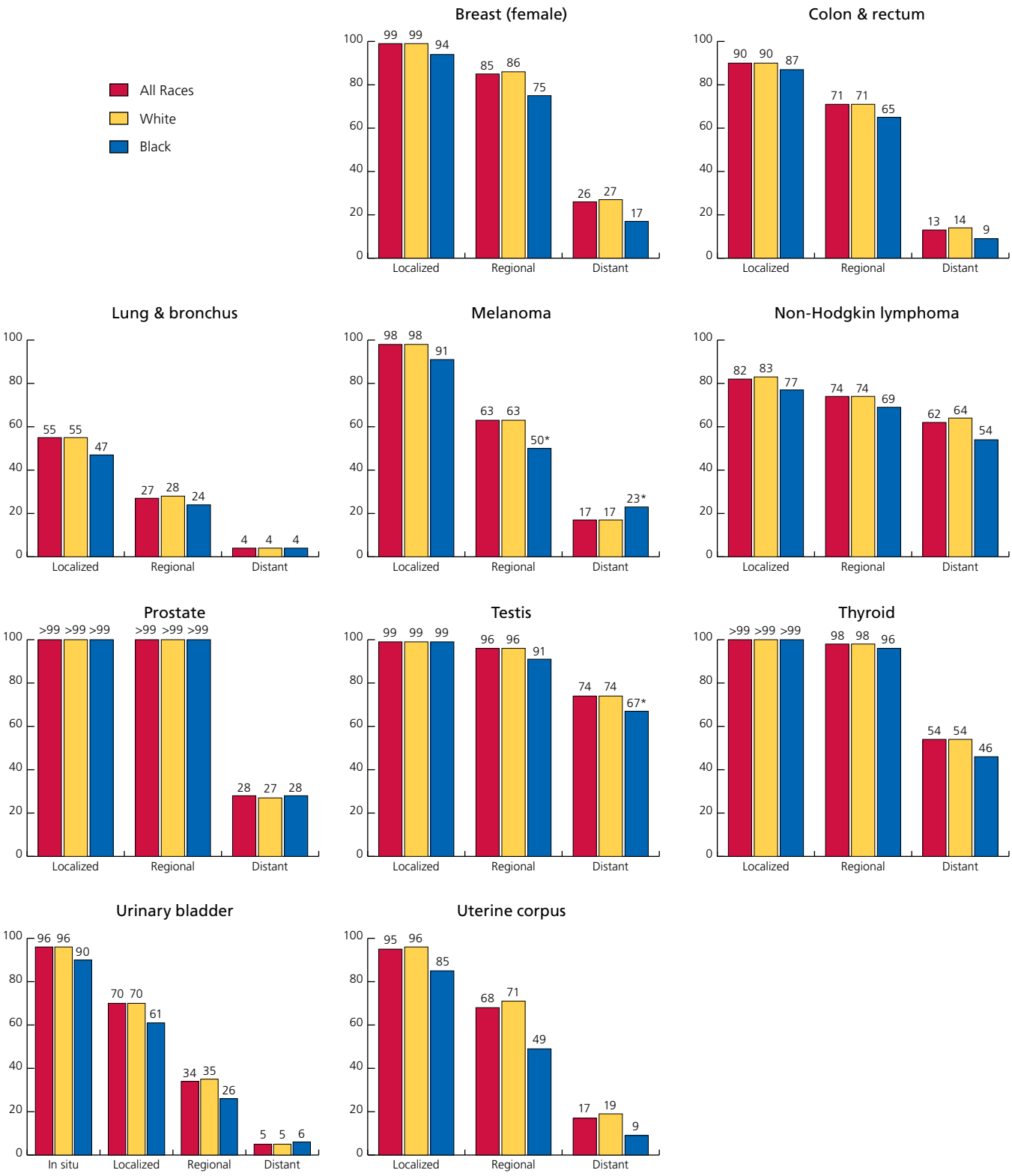
Figure 5. Five-year Relative Survival Rates (%) by Cancer Type, Race, and Stage at Diagnosis, 2005-2011



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

Source: Howlader, et al, 2015.[57]

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continue to be less likely to be diagnosed with localized disease (Figure 4, page 8) and have lower survival within each stage (Figure 5, page 9). 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.[59-61]

Short- and long-term health effects

Lymphedema of the arm is swelling caused by removal of or damage to 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 sentinel lymph node biopsy will develop arm lymphedema.[62] Some evidence suggests that certain exercises, when supervised by a trained professional, and other forms of cancer rehabilitation may reduce the risk and lessen the severity of this condition.[63-65]

Other long-term local effects of surgical and radiation treatment can include numbness, tingling, or tightness in the chest wall, arms, or shoulders. Some women have persistent nerve pain in the chest wall, armpit, and/or arm after surgery. Although this type of pain is often referred to as postmastectomy pain syndrome, it can occur after BCS as well. Studies have shown that 25% to 60% of women develop chronic pain after breast cancer treatment.[66]

In addition, women diagnosed and treated for breast cancer at younger ages may experience impaired fertility and premature menopause and are at increased risk of osteoporosis.[67] Treatment with aromatase inhibitors, generally reserved for postmenopausal women, can also cause osteoporosis, as well as muscle pain and joint stiffness/pain,[20, 68] while tamoxifen treatment can slightly increase the risk of endometrial cancer (cancer of the lining of the uterus) and blood clots.[69] Hormonal treatments for breast cancer can also cause menopausal symptoms, such as hot flashes, night sweats, and vaginal dryness, which can lead to pain during intercourse. Negative body image is an important concern in breast cancer patients, affecting an estimated 31% to 67% of patients.[70]

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

Cancers in Children and Adolescents

It is estimated that there were 65,190 cancer survivors ages 0-14 (children) and 47,180 survivors ages 15-19 (adolescents) living in the US as of January 1, 2016, and an additional 10,380 children ages 0-14 will be diagnosed in 2016.

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:

- Leukemia (30%)
- Brain and central nervous system (CNS) tumors (26%)
- Soft tissue sarcomas (7%), about half of which are rhabdomyosarcoma (a cancer of muscle cells that most often occurs in the head and neck, genitourinary area, and extremities)

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

- Brain and CNS tumors (20%)
- Leukemia (14%)
- Hodgkin lymphoma (13%)

Some other common pediatric cancers include:

- Non-Hodgkin lymphoma (NHL), which, like Hodgkin lymphoma, is more common in adolescents than in children; lymphomas often affect lymph nodes, but may also involve the bone marrow and other organs
- Neuroblastoma, a cancer of the nervous system that is most common in children younger than 5 years of age and usually appears as a swelling in the abdomen or neck
- Wilms tumor (also known as nephroblastoma), a kidney cancer that usually occurs in children under 5 years of age and may be recognized as a swelling in the abdomen
- Retinoblastoma, an eye cancer that typically is 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 appears as sporadic pain in the affected bone that may worsen at night or with activity, eventually progressing to local swelling
- Ewing sarcoma, another type of cancer that usually arises in the bone, is also 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, targeted therapy, or immunotherapy), chosen based on cancer type and stage. Treatment most commonly occurs in specialized centers and is coordinated by a team of experts, including pediatric oncologists, surgeons, and nurses; social workers; child life specialists; and psychologists.

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.[71] Studies have shown that for adolescent patients diagnosed with acute lymphocytic leukemia (ALL), outcomes are improved on pediatric, as opposed to adult, protocols.[72]

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.[73]

The 5-year relative survival rate for all childhood (ages 0-14) cancers combined has improved markedly over the past 30 years, from 58% during 1975-1977 to 83% during 2005-2011, due to new and improved treatments. Although improvements in survival among adolescents have not been as dramatic as those in children, the current overall 5-year survival for adolescents (84%) is similar.[57,74]

Cancer survival for children and adolescents varies considerably depending on cancer type, patient age, and other characteristics. For example, the 5-year relative survival for children (ages 0-14) is 98% for Hodgkin lymphoma, 97% for retinoblastoma, 92% for Wilms tumor, 89% for ALL and for NHL, 78% for neuroblastoma, 72% for brain and CNS tumors (excluding benign and borderline brain tumors), 69% for rhabdomyosarcoma, and 69% for osteosarcoma.

Short- and long-term health effects

Children diagnosed with cancer may experience treatment-related side effects not only during treatment, but many years later. Aggressive treatments used for childhood cancers, especially in the 1970s and 1980s, have resulted in a number of late effects, including an increased risk of second cancers.[75] A large follow-up study of pediatric cancer survivors found that almost 10% developed a second cancer (most commonly female breast, thyroid, and bone) over the 30-year period following initial diagnosis.[76] Another study found that 50% of these survivors had developed a severe or life-threatening chronic health condition by 50 years of age.[77] Among childhood cancer survivors exposed to cancer treatments potentially toxic to the heart or lungs (e.g., chest radiation, anthracyclines), more than half experience heart or lung problems.[78]

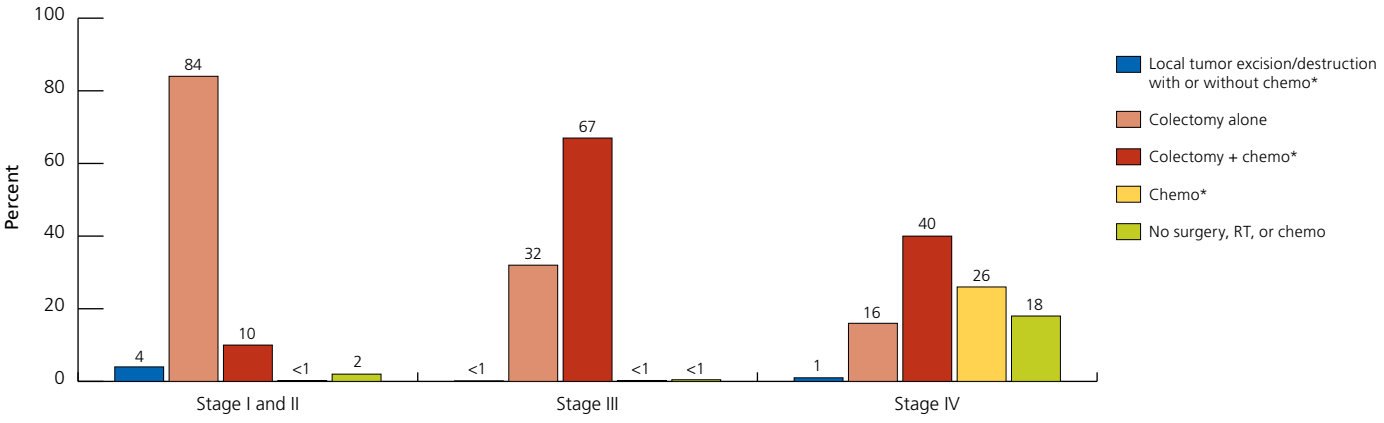
Although treatment improvements in more recent eras have substantially reduced long-term mortality among childhood cancer survivors,[75] even many newer, less toxic, therapies increase the risk of serious health conditions. Treatments affecting the reproductive organs may cause infertility in both male and female patients.[79,80] As a result, 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 managing late effects in survivors of childhood cancer. Visit the COG website at **survivorshipguidelines.org** for more information on childhood cancer management.

See the special section of *Cancer Facts & Figures 2014*, available online at **cancer.org/statistics**, for detailed information on childhood and adolescent cancer.

Colon and Rectum

It is estimated that as of January 1, 2016, there were more than 1.4 million men and women living in the US with a previous colorectal cancer diagnosis, and an additional 134,490 will be diagnosed in 2016. The median age at diagnosis for colorectal cancer is 66 for males and 70 for females. Rectal cancer patients tend to be younger at diagnosis than colon cancer patients (median age 63 versus 70, respectively).

Figure 6. Colon Cancer Treatment Patterns (%) by Stage, 2013

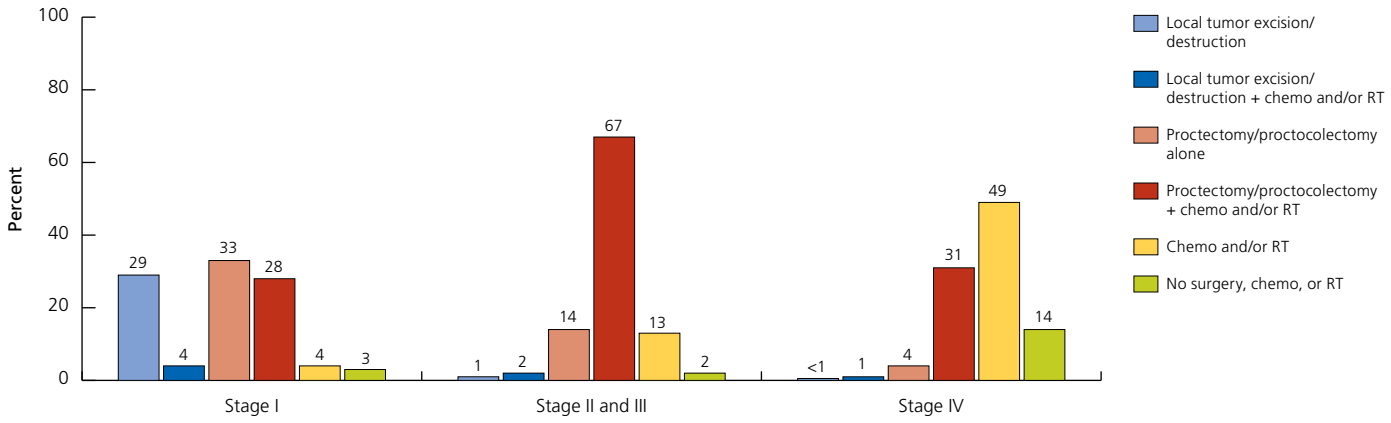


Chemo = chemotherapy and includes targeted therapy and immunotherapy drugs; Colectomy = removal of all or part of the colon; RT = radiation therapy.
*A small number of these patients receive radiation therapy.

Source: National Cancer Data Base, 2013.[102]

American Cancer Society, Surveillance and Health Services Research, 2016

Figure 7. Rectal Cancer Treatment Patterns (%) by Stage, 2013



Chemo = chemotherapy and includes targeted therapy and immunotherapy drugs; Proctocolectomy = remove of the rectum and all or part of the colon; Proctectomy = removal of the rectum; RT = radiation therapy.

Source: National Cancer Data Base, 2013.[102]

American Cancer Society, Surveillance and Health Services Research, 2016

Use of recommended colorectal cancer screening tests can both detect cancer early, when treatment is more effective, and prevent cancer, through the detection and removal of precancerous polyps. However, in 2013, only 59% of adults 50 years of age and older reported receiving colorectal cancer screening according to guidelines.[81]

Treatment and survival

Treatment for cancers of the colon and rectum varies by tumor location, characteristics, and stage. Surgical procedures for colorectal cancer include local tumor excision or destruction, 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). The majority of early stage (I and II) colon cancers are treated with colectomy alone (84%), while most patients with stage III disease receive chemotherapy in addition to surgery (67%) (Figure 6, page 11).

For rectal cancer, 61% of stage I patients have a proctectomy or proctocolectomy, about half of whom also receive radiation and/or chemotherapy (Figure 7). In contrast to colon cancer, stage II and III rectal cancers are often treated with chemotherapy combined with radiation before surgery (neoadjuvant). Chemotherapy is the main treatment for metastatic rectal cancer, although in some cases surgery is possible. A number of targeted drugs are also available to treat metastatic disease.

For patients undergoing surgery, an ostomy (creation of an abdominal opening, or stoma, for elimination of body waste) may be needed. A colostomy is when a stoma is created from the large intestine, and an ileostomy is when it is created from the small intestine. In many cases, once the colon or rectum heals, the stoma is closed and the ends of the large intestine reconnected in a procedure called colostomy reversal. Rectal cancer patients require a colostomy more often than colon cancer patients (29% versus 12%, respectively).[82] A permanent colostomy may be required if the anus and the sphincter muscle are removed during surgery.

The 5- and 10-year relative survival rates for colorectal cancer are 65% and 58%, respectively. When colorectal cancer is detected at an early stage, the 5-year survival rate is 90% (Figure 5, page 9); however, only 39% of cases are diagnosed at this stage (Figure 4, page 8), in part due to the underuse of screening.

Short- and long-term health effects

Long-term survivors of colorectal cancer report a good overall quality of life compared with that of the general population, but higher rates of depression.[83] In addition, some difficulty with chronic diarrhea occurs in about one-half of colorectal cancer survivors.[84] Bowel dysfunction (including increased stool frequency, incontinence, and perianal irritation) is common among rectal cancer survivors, especially those treated with pelvic radiation.[85, 86] In addition, survivors may suffer from bladder dysfunction, sexual dysfunction, and negative body image.[40, 87] Many of these issues are more common in rectal cancer survivors, particularly those with a colostomy.[88] A trained ostomy therapist may be able to address several of these concerns, as well as issues that arise from colostomy care, such as skin irritation and dietary considerations.[89]

Recurrence is not uncommon among colorectal cancer survivors,[90, 91] although the exact percentage is unknown because population-based cancer registries do not collect these data.

These 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.[92]

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

Leukemia and Lymphoma

It is estimated that as of January 1, 2016, there were 407,950 leukemia survivors living in the US, and an additional 60,140 people will be diagnosed with leukemia in 2016. 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).

Although leukemia is the most common cancer in children ages 0-14, the majority (92%) of leukemia patients are diagnosed at ages 20 and older.[93] AML and CLL are the most common types of leukemia diagnosed in adults, whereas ALL is the most common type diagnosed in children and adolescents, accounting for 80% of leukemias in children and 54% in adolescents. The median age at diagnosis for ALL is 14; the median ages at diagnosis for CLL, AML, and CML are 71, 67, and 64, respectively (Figure 2, page 5).

Lymphomas are cancers that begin in cells of the immune system called lymphocytes. There are two major 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, 2016, there were 219,570 HL survivors and 686,370 NHL survivors, and that 8,500 and 72,580 new cases of HL and NHL, respectively, will be diagnosed in 2016.

Both HL and NHL can occur at any age; however, the majority (64%) of HL occurs before age 50, whereas most cases of NHL (85%) occur in those age 50 and older (Figure 2, page 5).

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 the disease progresses quickly and is rapidly fatal in the absence of treatment.

Chemotherapy is the standard treatment for AML. Treatment has two phases. The first, called induction, is designed to clear all evidence of leukemia cells from the blood and bone marrow, putting the disease into complete remission. The goal of the second phase, called consolidation, is to kill any remaining leukemia cells that cannot be seen and would cause relapse if left untreated. Many older adults (among whom the disease is most common) are not able to tolerate the most aggressive and effective regimens.[94] Appropriate treatment is based on both the patient's age and health condition and the molecular characteristics of the patient's cancer cells. Some patients may undergo allogeneic stem cell transplantation (in which the transplanted cells come from a donor whose tissue type closely matches the patient's); these patients may receive chemotherapy alone or with radiation as part of a conditioning regimen prior to stem cell transplantation.

Approximately 60% to 85% of adults ages 60 and younger with AML can expect to attain complete remission status following the first phase of treatment, and 35% to 40% of patients in this age group will be cured.[94, 95] In contrast, 40% to 60% of patients older than 60 will achieve complete remission, and only 5% to 15% will be cured. About 4% of AML cases occur in children and adolescents (ages 0-19),[93] for whom the prognosis is substantially better than among adults. The 5-year relative survival for children and adolescents is 65%, but declines to 50%, 32%, and 6% for patients ages 20-49, 50-64, and 65 years and older, respectively.[96]

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 almost always have a distinctive genetic abnormality called the Philadelphia chromosome. There are three phases of CML: chronic, accelerated, and blast. 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; and the blast phase is the most aggressive and has more severe symptoms and may rapidly lead to death.

The standard treatment for CML is a type of targeted drug called a tyrosine kinase inhibitor (e.g., imatinib). These drugs are very effective at inducing remission and decreasing progression to the accelerated phase, but must be taken indefinitely to keep the disease in check. If the leukemia becomes resistant to one tyrosine kinase inhibitor, another may be tried. For cancers that are resistant to tyrosine kinase inhibitors, chemotherapy or stem cell transplantation may be used. In part due to the discovery of these targeted therapies, the 5-year survival rate for CML has nearly doubled from 31% for during 1990-1992 to 63% for those diagnosed during 2005-2011.[57]

ALL. Acute lymphocytic leukemia (also called acute lymphoblastic leukemia) is a disease in which too many immature lymphocytes (a type of white blood cell) are produced in the bone marrow. It progresses rapidly without treatment. More than half (56%) of all ALL cases are diagnosed in patients younger than 20 years of age.[93]

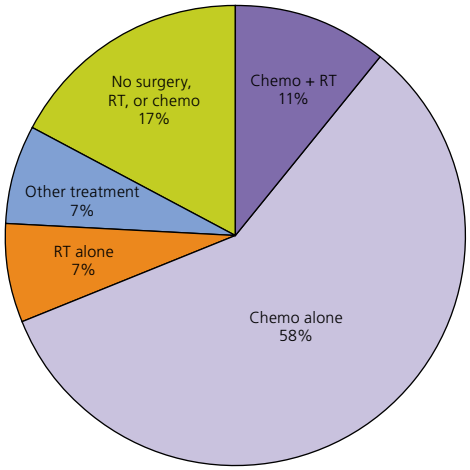
Treatment is generally in three phases and consists of 4-6 weeks of induction chemotherapy (given to induce remission), often administered in the hospital, followed by several months of consolidation (or intensification) therapy, and 2-3 years of maintenance chemotherapy.[97] Some ALL patients have a similar chromosomal abnormality as occurs in CML and benefit from the addition of a tyrosine kinase inhibitor. More than 95% of children and 78%-92% of adults with ALL attain remission. Stem cell transplantation is recommended for some patients 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.[57] In addition, the black-white 5-year survival disparity for children with ALL has declined from a 21 percentage point difference during 1980-1984 (49% versus 70%, respectively) to a 3 percentage point difference during 2005-2011 (89% versus 92%, respectively).[96] Survival dramatically declines with increasing age; the current 5-year survival rate is 46% for ages 20 to 39, 30% for ages 40 to 64, and 15% for age 65 and older.

CLL. Chronic lymphocytic leukemia is characterized by the overabundance of mature lymphocytes in the blood and bone marrow. It usually progresses slowly and is most commonly diagnosed in older adults, with 95% of cases occurring in those age 50 and older (Figure 2, page 5). Treatment is not likely to cure and is generally reserved for symptomatic patients or those who have low blood cell counts of normal (non-leukemic) cells or other complications. For patients with early disease, active surveillance (carefully monitoring over time for disease progression) is a common approach. For patients with more advanced disease, available treatments include chemotherapy combined with immunotherapy and targeted therapies, which can delay the progression of disease, but it often is not clear whether these treatments extend survival.[98-100] The overall 5-year relative survival for CLL is 82%; however, there is a large variation in survival among individual patients, ranging from several months to normal life expectancy.[96]

HL. Hodgkin lymphoma 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 5). 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 cases, and is characterized by "popcorn" cells.[93] NLPHL is a more slow-growing disease with a generally favorable prognosis.[101]

Figure 8. Non-Hodgkin Lymphoma Treatment Patterns (%), 2013



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

Source: National Cancer Data Base, 2013.[102]
American Cancer Society, Surveillance and Health Services Research, 2016

Classical HL is usually treated with multi-agent chemotherapy (88%), sometimes in combination with radiation therapy (30% of chemotherapy recipients), although the use of radiotherapy is declining.[102] If initial treatment is not effective, a different chemotherapy regimen may be tried, sometimes followed by autologous ("patient's own") stem cell transplantation. Other treatment options include radiation or the targeted drug brentuximab vedotin. For patients with NLPHL, radiation therapy alone may be appropriate for early stage disease.[101] For those with later-stage disease, chemotherapy plus radiation, as well as the monoclonal antibody rituximab, may be recommended.

The 5- and 10-year survival rates for all HL combined are 86% and 80%, respectively.[96] Five-year survival is higher for NLPHL than for CHL – 94% versus 85%, respectively.

NHL. The most common types of non-Hodgkin lymphoma are diffuse large B-cell lymphoma (DLBCL), representing 37% of cases, and follicular lymphoma, representing 20% of cases.[93] DLBCLs grow quickly, yet most patients with localized disease and about 50% with advanced disease are cured with treatment.[103, 104] Follicular lymphomas tend to grow slowly and often do not require treatment until symptoms develop; however, many cases are not curable.[105] Some cases of follicular lymphoma transform into DLBCL.

Approximately 69% of NHL patients receive chemotherapy (including monoclonal antibody therapy), some of whom also receive radiation therapy; radiation alone is used less often (7%) (Figure 8). About 17% of patients receive no initial treatment. If

NHL persists or recurs after standard treatment, stem cell transplantation may be an option that can cure some patients.

Five-year survival is 86% for follicular lymphoma and 61% for DLBCL; 10-year survival declines to 77% and 53%, respectively.[57]

Short- and long-term health effects

Some survivors, such as those who received stem cell transplant, have recurrent infections and low blood cell counts that may require blood transfusions. In addition, allogeneic transplantation for acute leukemias may lead to chronic graft-versus-host disease, which can cause skin changes, dry mucous membranes (eyes, mouth, vagina), joint pain, weight loss, shortness of breath, and fatigue.[106]

In addition, leukemia treatment regimens that involve anthracyclines can have heart-damaging effects. Chest radiation for Hodgkin lymphoma also increases the risk for various heart complications (e.g., valvular heart disease and coronary artery disease), as well as breast cancer among women treated in childhood or adolescence, and possibly diabetes mellitus.[107, 108] Certain chemotherapy drugs, as well as high-dose chemotherapy used with stem cell transplant, can lead to infertility. In the past, most children with ALL received cranial radiation therapy, which is associated with long-term cognitive deficits.[109] This treatment is used less frequently and in lower dosages today.

Lung and Bronchus

It is estimated that there were 526,510 men and women living in the US with a history of lung cancer as of January 1, 2016, and an additional 224,390 will be diagnosed in 2016. The median age at diagnosis for lung cancer is 70.

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.[110] The American Cancer Society has issued guidelines for lung cancer screening for current or former (quit within the previous 15 years) adult smokers with at least a 30-year pack history.[111]

Treatment and survival

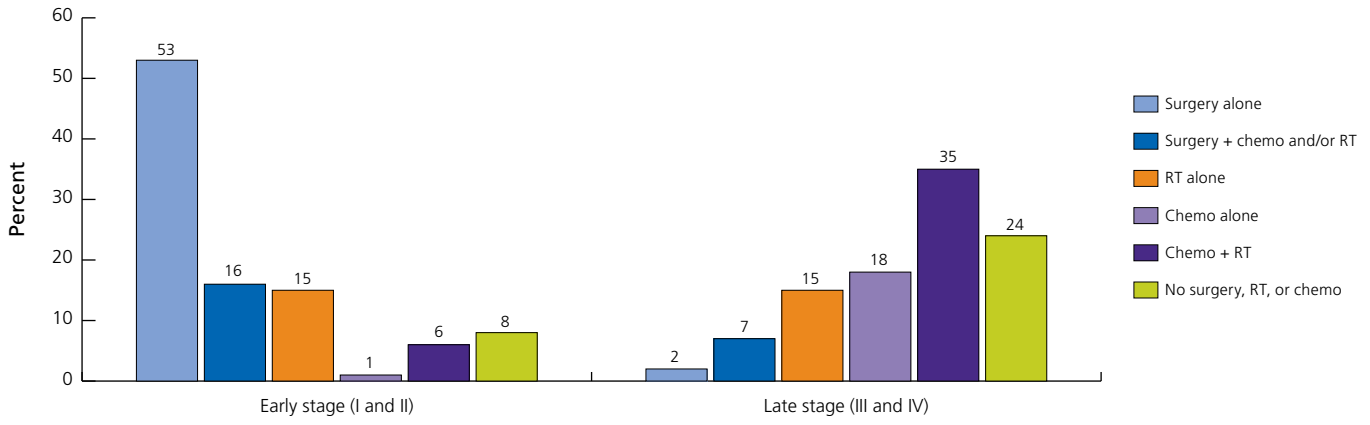
Lung cancer is classified as small cell (13% of cases) or non-small cell (83%) for the purposes of treatment (3% of cases lack information on cell type).[57] Based on type and stage of cancer, treatment may include surgery, radiation therapy, chemotherapy, targeted therapies, and/or immunotherapy.

Most patients with small cell lung cancer (SCLC) receive chemotherapy.[102] In addition, some patients also receive concurrent radiation to the chest, and some receive cranial radiation therapy to help prevent later development of brain metastases.

For early stage (stage I and II) NSCLC, the majority (69%) of patients undergo surgery, with almost one-fourth also receiving chemotherapy and/or radiation (Figure 9). Most patients with advanced-stage (stage III and IV) NSCLC are treated with chemotherapy with or without radiation (53%). There are a number of targeted drugs available to treat advanced NSCLC, but some are only useful in treating cancers with certain gene mutations. Immunotherapy drugs have also recently been approved to treat some types of NSCLC.

The 1- and 5-year relative survival rates for lung cancer are 44% and 17%, respectively.[96] Because symptoms usually do not appear until the disease has already spread to other parts of the

Figure 9. Non-small Cell Lung Cancer Treatment Patterns (%) by Stage, 2013



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

Source: National Cancer Data Base, 2013.[102]

American Cancer Society, Surveillance and Health Services Research, 2016

body, less than 1 in 5 lung cancer patients are diagnosed at a localized stage, for which the 5-year survival rate is 55% (Figure 4, page 8, and Figure 5, page 9). Five-year survival for SCLC (7%) is lower than that for NSCLC (21%) overall and is also lower for each stage.[57]

Short- and long-term health effects

Many lung cancer survivors have impaired lung function, especially if they have had surgery and had preexisting lung problems due to smoking.[112] In some cases respiratory therapy and medications can improve fitness and allow these survivors to resume normal daily activities. Lung cancer survivors who are current or former smokers are at increased risk for additional smoking-related cancers, especially head and neck or urinary tract cancers, as well as second lung cancers and other health problems. Survivors may feel stigmatized because of the social perception that lung cancer is a self-inflicted disease, which can be particularly difficult for those who never smoked.[113] While physicians and patients may feel it is too late to stop smoking once lung cancer is found, data suggest otherwise.[114, 115]

Melanoma

It is estimated that there were more than 1.2 million melanoma survivors living in the US as of January 1, 2016, and an additional 76,380 people will be diagnosed in 2016. Melanoma incidence rates have continued to increase in men but recently stabilized in women.[116] Women tend to be diagnosed at a younger age than men (58 versus 65 years of age, respectively), reflecting differences in occupational and recreational exposure to ultraviolet radiation, as well as frequency of health care interactions, by sex and age.

Treatment and survival

Surgery to remove the tumor and surrounding tissue is the primary treatment for most melanomas. Patients with stage III melanoma may be offered adjuvant immunotherapy with interferon for about a year, but side effects often make this treatment very difficult to tolerate. Treatment for patients with stage IV melanoma has changed in recent years and typically includes new immunotherapy or targeted therapy drugs.[117] About half of all melanomas of the skin have mutations in the *BRAF* gene, for which several targeted drugs have been shown to improve survival for patients with metastatic disease.[118, 119] Almost one-half (46%) of patients with metastatic disease who receive either chemotherapy or immunotherapy also receive radiation therapy.[102]

The 5- and 10-year relative survival rates for people with melanoma are 92% and 89%, respectively.[96] About 84% of melanomas are diagnosed at a localized stage, for which the 5-year relative survival is 98% (Figure 4, page 8, and Figure 5, page 9).

Short- and long-term health effects

Depending on the size and location of the melanoma, removal of these cancers can be disfiguring. Patients who had several lymph nodes removed during surgery may develop lymphedema. Immunotherapy drugs used to treat melanoma can cause a number of side effects, including inflammation of the lungs, colon, or kidneys, and endocrine disorders (e.g., hypothyroidism, adrenal insufficiency). In addition, 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.[120] Thus, it is important for survivors to monitor their skin for new skin cancers and limit sun exposure.

Prostate

It is estimated that there were 3.3 million men with a history of prostate cancer living in the US as of January 1, 2016, and an additional 180,890 men will be diagnosed in 2016. The median age at diagnosis is 66 (Figure 2, page 5). Aside from skin cancer, prostate cancer is the most frequently diagnosed cancer in men. Men diagnosed with prostate cancers in the US are most often identified with an abnormal prostate-specific antigen (PSA) test. However, routine use of this test for screening men at average risk of the disease is not recommended. The American Cancer Society recommends that beginning at age 50, men who are at average risk of prostate cancer and have a life expectancy of at least 10 years have a conversation with their health care provider about the benefits and limitations of PSA screening.

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 rather than immediate treatment is a commonly recommended approach for early stage cancer, particularly for men with less aggressive disease or for those who are older or who have more serious comorbid conditions.[121-123] The percentage of prostate cancer patients with less aggressive, localized disease who undergo active surveillance instead of immediate treatment has increased in recent years among both younger and older men.[124]

Most (92%) prostate cancers are diagnosed in the local or regional stages, for which the 5-year relative survival rate approaches 100%. Almost half (51%) of men ages 64 or younger are initially treated with radical prostatectomy (removal of the prostate along with nearby tissues with or without radiation, whereas radiation therapy alone is the most common treatment for men ages 65 to 74 (36%) (Figure 10). About half of men ages 75 and older undergo active surveillance. Some men are also treated with hormonal androgen deprivation therapy (ADT).

Although survival rates are favorable for patients with early stage disease treated with surgery or radiotherapy (with or without ADT), both are associated with substantial risk of physical impairment (sexual, urinary, and bowel).[125, 126]

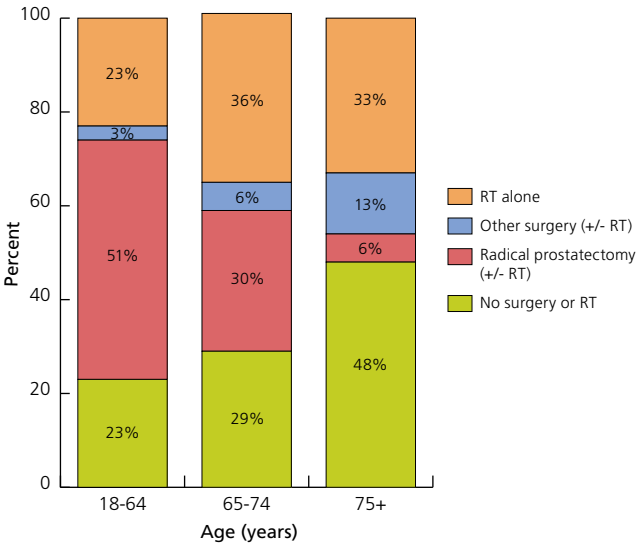
More advanced prostate cancer may be treated with ADT, chemotherapy, bone-directed therapy, radiation therapy, and/or other treatments. ADT is generally the first treatment used for advanced disease and can often control the cancer for long periods, also helping to relieve pain and other symptoms. For men with advanced cancers that do not respond to traditional ADT, newer hormone therapies may be effective.[127-130]

Over the past 35 years, the 5-year relative survival rate for all stages combined has increased from 68% to 99%.[57] According to the most recent data, 10- and 15-year relative survival rates are 98% and 95%, respectively.[96]

Short- and long-term health effects

Many prostate cancer survivors who have been treated with surgery or radiation experience temporary incontinence, erectile dysfunction, and/or bowel complications.[131] Patients receiving hormonal treatment may experience loss of libido, hot flashes, night sweats, irritability, and breast development. Hormonal therapy also increases the risk of anemia, osteoporosis, and metabolic syndrome, and may increase the risk of cardiovascular disease.[132]

Figure 10. Prostate Cancer Primary Treatment Patterns (%), by Age, 2010-2012



Radical prostatectomy = removal of the prostate along with nearby tissues; RT = radiation therapy.

Source: Surveillance Epidemiology and End Results (SEER) Program, SEER 18 Registries.[142]

American Cancer Society, Surveillance and Health Services Research, 2016

Testis

It is estimated that there were 266,550 testicular cancer survivors in the US as of January 1, 2016, and an additional 8,720 men will be diagnosed in 2016. Testicular germ cell tumors (TGCTs) account for more than 97% of testicular cancers.[93] These tumors arise from testicular cells that normally develop into sperm cells. The median age at diagnosis for testicular cancer is 33 (Figure 2, page 5), much younger than most other cancers.

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.

Treatment and survival

Treatment of almost all TGCTs begins with surgery to remove the testicle in which the tumor arose. After surgery, early stage (stage I and II) seminomas are sometimes treated with radiation (31%) or chemotherapy (22%) (Figure 11, page 18). Over the past decade, postsurgery active surveillance has become an increasingly preferred management option for patients with stage I seminomas,[133] and long-term study results support this treatment strategy.[134] Advanced-stage (stage III and IV) seminomas are usually treated with surgery followed by chemotherapy alone (66%) (Figure 11, page 18).

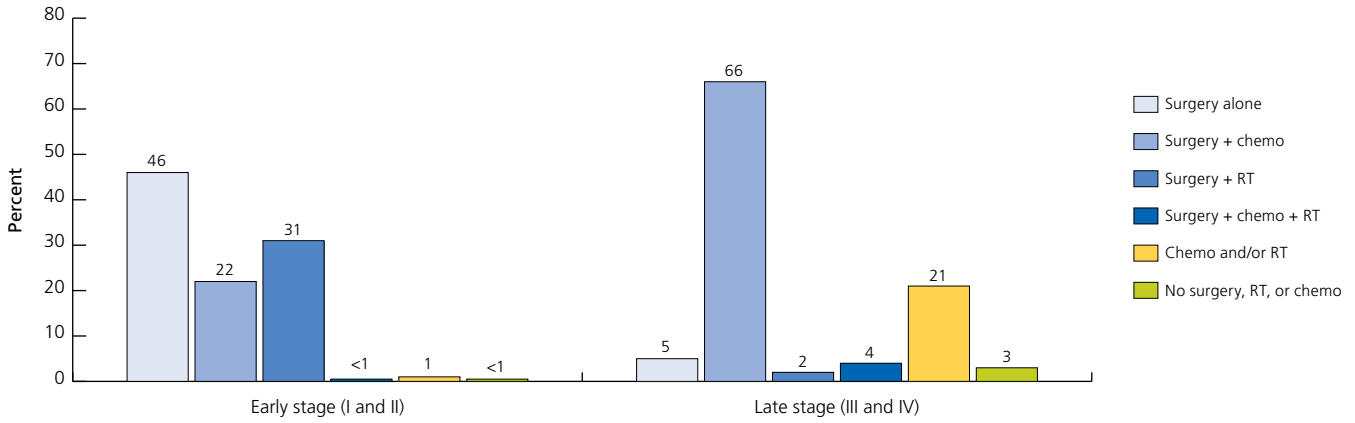
For men with early stage (stage I and II) nonseminomas, almost half are treated with surgery alone, and approximately 20% undergo retroperitoneal lymph node dissection (RPLND), which is recommended to reduce the likelihood of recurrence (Figure 12, page 18). Men with late stage (III and IV) nonseminomas are usually treated with chemotherapy after surgery.

The 5-, 10- and 15-year relative survival rates for testicular cancer are 99%, 95%, and 95%, respectively. Most testicular cancers (68%) are detected at a local stage because of a lump on the testicle; 5-year relative survival for this stage is 99% (Figure 4, page 8, and Figure 5, page 9). Even cancers diagnosed at a distant stage may be successfully treated, with a 5-year relative survival of 74%.

Short- and long-term health effects

Testicular cancer survivors tend to be younger than men with most other types of cancer, and they are often concerned about sexual and fertility problems after treatment. Although most men with one healthy testicle produce sufficient male hormones and sperm to continue sexual relations and father children, sperm banking is recommended prior to treatment if possible (fertility may already be impaired before treatment). Men with cancer in both testicles require lifelong hormone replacement after the testicles are removed. Men treated with chemotherapy have increased risks of coronary artery disease as they age, and

Figure 11. Treatment Patterns (%) for Seminomatous Testicular Germ Cell Tumors by Stage, 2009-2013

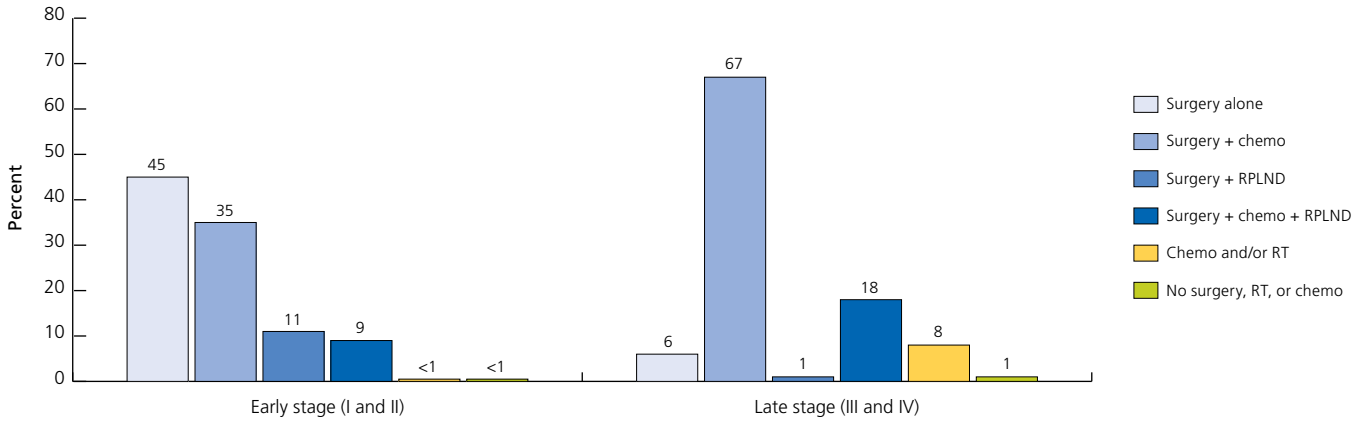


Chemo = chemotherapy and includes targeted therapy and immunotherapy drugs; RT = radiation therapy.

Source: National Cancer Data Base, 2013.[102]

American Cancer Society, Surveillance and Health Services Research, 2016

Figure 12. Treatment Patterns (%) for Nonseminomatous Testicular Germ Cell Tumors by Stage, 2009-2013



Chemo = chemotherapy and includes targeted therapy and immunotherapy drugs; RPLND = retroperitoneal lymph node dissection; RT = radiation therapy.
NOTE: A small proportion of patients (<1% of early stage and about 5% of late stage) who underwent surgery also had RT.

Source: National Cancer Data Base, 2013.[102]

American Cancer Society, Surveillance and Health Services Research, 2016

should be particularly mindful of risk factors such as high cholesterol, high blood pressure, obesity, and smoking. Consultation about fertility risks prior to treatment and referral for sperm banking as appropriate are both important in promoting quality of life outcomes.

Thyroid

It is estimated that there were 805,750 people living with a past diagnosis of thyroid cancer in the US as of January 1, 2016, and an additional 64,300 will be diagnosed in 2016. 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 partly due to increased detection because of more sensitive diagnostic procedures, resulting in some overdiagnoses of papillary thyroid cancers.[135] However, observed increases in rates of follicular thyroid cancer, as well as increases across tumor size and stages, may be associated with the rise in risk factors such as obesity.[136-138]

Thyroid cancer commonly occurs at a younger age than most other adult cancers, with a median age at diagnosis of 54 for males and 49 for females.[57]

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 tend to be more difficult to treat because they do not respond to radioactive iodine treatment.[57, 139] These types of thyroid cancer also typically grow more quickly and have often metastasized by the time they are diagnosed.

The first choice of treatment in nearly all cases is surgery, with patients receiving either total (86%) or partial (12%) thyroidectomy (removal of the thyroid gland).[102] More than half (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.[140] If the thyroid has been removed completely, thyroid hormonal replacement therapy is required to maintain normal metabolism 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. Radiation therapy may be given after surgery for more advanced cancers to reduce the chance of recurrence. Targeted drugs or chemotherapy may be used for medullary carcinomas that cannot be treated with surgery. Anaplastic thyroid cancers are often widespread at the time of diagnosis, making surgery difficult or impossible. Radiation therapy and/or chemotherapy may be used to treat these cancers.

The 5-year relative survival rate for thyroid cancer patients diagnosed during 2005-2011 is 98%, although survival varies by patient age at diagnosis, extent of disease, and cancer type. For example, the 5-year survival rate is 88% for medullary thyroid cancer and 9% for anaplastic thyroid cancer.[96] Overall, 68% of thyroid patients are diagnosed at a localized stage, for which 5-year relative survival approaches 100% (Figure 4, page 8, and Figure 5, page 9). Notably, blacks are more likely than whites to be diagnosed at a local stage (78% versus 68%, respectively), yet have lower overall survival.

Short- and long-term health effects

Patients requiring thyroid hormone replacement therapy must have their hormone levels monitored to prevent hypothyroidism, which can cause cold intolerance and weight gain. Surgery can also damage nerves to the larynx and lead to voice changes. Treatment with radioactive iodine has been linked to an increased risk of leukemia.[141] About 25% of medullary thyroid cancers occur as part of a familial (genetic) syndrome; these patients may be screened for other cancers and referred for genetic counseling and possible testing.[139]

Urinary Bladder

It is estimated that there were 765,950 urinary bladder cancer survivors living in the US as of January 1, 2016, and an additional 76,960 cases will be diagnosed in 2016. Bladder cancer incidence is about 4 times higher in men than in women. More than 70% of patients with bladder cancer are diagnosed with non-muscle-invasive disease (includes both in situ and invasive cancer that is present only in the very inner layers of bladder cells).[142] 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 (TURBT). This endoscopic surgery may be followed by intravesical treatment (injected directly into the bladder) with either a chemotherapy drug (22%) or immunotherapy with bacillus Calmette-Guerin (BCG) (29%).[102]

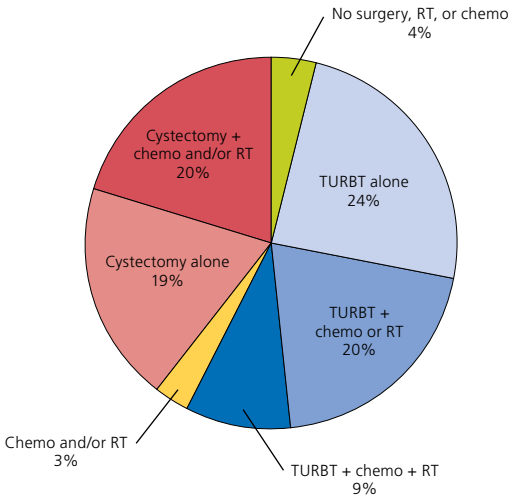
Among patients with muscle-invasive disease, about half receive TURBT and 39% receive cystectomy (a surgery that removes all or part of the bladder, as well as the surrounding fatty tissue and lymph nodes) with or without chemotherapy and/or radiation (Figure 13, page 20). In appropriately selected cases, TURBT followed by combined chemotherapy and radiation is as effective as cystectomy at preventing recurrence.[143-145] Chemotherapy is usually the first treatment for cancers that have spread to other organs, but other treatments might be used as well.

For all stages combined, the 5-year relative survival rate is 77% (Figure 2, page 5). Survival declines to 70% at 10 years and 65% at 15 years after diagnosis.[96] In situ urinary bladder cancer is diagnosed in 51% of cases, for which the 5-year survival rate is 96%. Thirty-five percent of patients are diagnosed with localized disease, for which 5-year survival is 81% for non-muscle invasive disease but drops to 47% for cancers that are muscle-invasive. For both types combined, 5-year survival is 34% and 5% for regional- and distant-stage disease, respectively.

Short- and long-term health effects

Posttreatment surveillance is crucial given the high rate of bladder cancer recurrence (ranging from 50%-90%).[146, 147] Surveillance can include cystoscopy (examination of the bladder with a small scope), urine cytology, and other urine tests for tumor markers. Patients with muscle-invasive disease may have additional tests, such as computed tomography scans of the chest, abdomen, and pelvis.

Figure 13. Muscle-invasive Bladder Cancer Treatment Patterns (%), 2013



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

Source: National Cancer Data Base, 2013.[102]

American Cancer Society, Surveillance and Health Services Research, 2016

Partial cystectomy results in a smaller bladder, sometimes causing the patient to have more frequent urination. Patients undergoing cystectomy in which the entire bladder is removed require urinary diversion with either a "new" bladder (known as a neobladder), created by connecting a small part of the intestine to the urethra, or a urostomy, which is a conduit that empties into a bag worn on the abdomen or uses an internal valve (requiring self-catheterization). Those with a neobladder retain most of their urinary continence after appropriate rehabilitation.[148] However, creation of a neobladder remains much less common than a urostomy (9% versus 91%), largely due to the fact that the procedure is technically complex and often only offered at large hospitals with experienced surgeons.[149] Younger, healthier patients and those who are male are also more likely to undergo the procedure. Most patients with muscle-invasive disease treated with TURBT combined with chemotherapy and radiotherapy maintain full bladder function and good quality of life.[150] 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 757,190 uterine corpus (upper part of the uterus) cancer survivors living in the US as of January 1, 2016, and an additional 60,050 women will be diagnosed in 2016. Uterine cancer is the second most common cancer among female cancer survivors, following breast cancer. The disease is often referred to as endometrial cancer because more than 90% of cases occur in the endometrium (lining of the uterine corpus); the majority of the remaining cases are uterine sarcomas.[93] The median age at diagnosis is 62 (Figure 2, page 5).

Treatment and survival

Uterine cancers are usually treated with surgery, radiation, hormonal therapy, and/or chemotherapy, depending on stage and cancer 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 69% of patients with early stage disease (stages I and II) (Figure 14). About 28% of early stage patients have high-risk disease and also receive radiation and/or chemotherapy in addition to surgery.

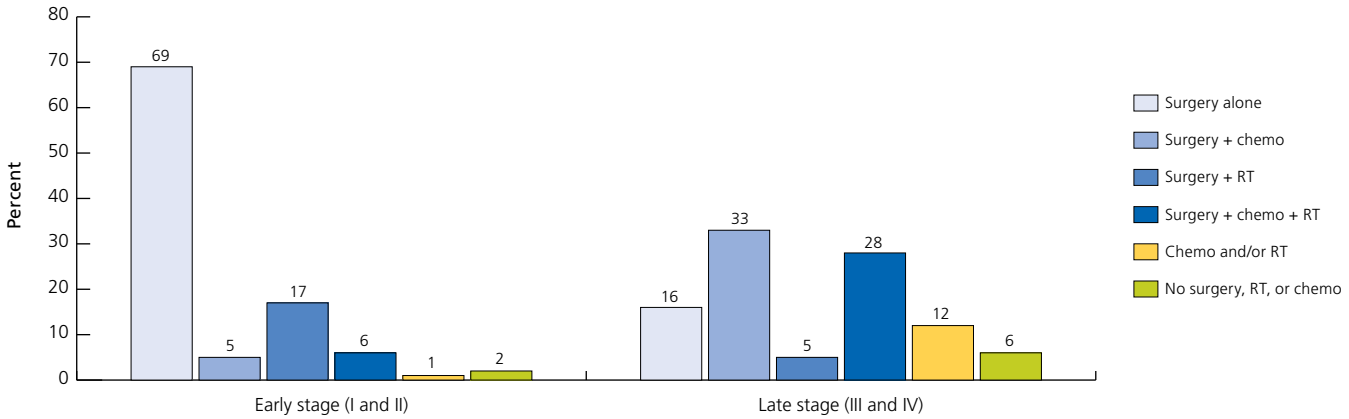
Among women with advanced-stage disease (stage III and IV), the majority (66%) receive surgery followed by radiation and/or chemotherapy (Figure 14). Clinical trials are currently assessing the most appropriate regimen of radiation and chemotherapy for women with metastatic or recurrent endometrial cancers.

The 5- and 10-year relative survival rates for cancer of the uterine corpus are 82% and 79%, respectively. About two-thirds of cases are diagnosed at a localized stage (usually because of postmenopausal bleeding), for which the 5-year survival is 95% (Figure 5, page 9). The 5-year survival for white women (84%) is substantially higher than for black women (62%) for all stages combined, and is also lower for each stage.[57]

Short- and long-term health effects

Any hysterectomy causes infertility. Bilateral salpingo-oophorectomy causes menopause in premenopausal women, which can result in symptoms such as hot flashes, night sweats, vaginal dryness, and osteoporosis. Sexual problems are commonly reported among uterine cancer survivors.[151] Removing lymph nodes in the pelvis can lead to a buildup of fluid in the legs (lymphedema), which occurs more often when radiation is given after surgery.[152]

Figure 14. Uterine Corpus Cancer Treatment Patterns (%), by Stage, 2013



Chemo = chemotherapy and includes targeted therapy and immunotherapy drugs; RT = radiation therapy.
Source: National Cancer Database, 2013.[102]

American Cancer Society, Surveillance and Health Services Research, 2016

Navigating the Cancer Experience: Diagnosis and Treatment

Newly diagnosed cancer patients and their families face numerous challenges and difficult decisions, such as selecting a doctor and treatment facility, that are even more overwhelming for patients who experience barriers to quality cancer care.

Choosing a Doctor

Choosing a doctor to treat cancer is one of the most important decisions for newly diagnosed cancer patients. Typically, the doctor who made the preliminary diagnosis, usually the patient's primary care physician, will recommend appropriate cancer specialists. There are three main types of cancer physicians or oncologists, based on the type of treatment service they provide: medical (those who treat cancer using chemotherapy and other drugs), surgical, and radiation. 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 treatment by performing reconstructive surgeries as part of cancer care, particularly for patients with breast or head and neck cancers.

Many physicians are often involved in planning and providing treatment and addressing patient and family quality of life concerns such as pain, distress, or return to work. Often, these specialists work together as a multidisciplinary cancer care team that consults regularly about the management of individual cases.

To aid in the selection of an oncologist, visit the American Society of Clinical Oncology's website, cancer.net, for a searchable online database of cancer specialists. 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.

Important considerations in choosing a cancer specialist include:

- Are they board-certified?
- Do they have experience with your specific cancer type?
- Do they accept your health insurance? (Most insurance plans have websites that can be searched for doctors by specialty; if not, you can contact your plan to determine if they work with the cancer specialist.)
- Do they have privileges at a hospital in your area?

Cancer patients should 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. Questions about how the doctor organizes cancer care with

Goals for Improving the Quality of Cancer Care

In 2013, the Institute of Medicine released a report titled *Delivering High-Quality Care: Charting a New Course for a System in Crisis*.[153] 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.

other members of the cancer treatment team, 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, are also appropriate. See "How to Choose a Doctor" at **cancer.org** for more information.

Choosing a Treatment Facility

There are many excellent cancer care centers throughout the US, and a number of resources are available to learn about them. Insurance coverage of treatment facilities may vary. Before going to the treatment facility, patients should contact their insurance plan to determine whether they contract with the treatment facility, and if so, how much will have to be paid out of pocket to receive care at that facility.

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 US for their delivery of cancer care. Hospitals with this special designation have met specific 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 of accredited programs is available on the CooC website, **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 cancer centers that excel in research. NCI support to cancer centers is intended to foster excellence in research across a broad spectrum of scientific and medical concerns relevant to cancer. Cancer centers achieve the NCI designation when they attain a critical mass of research that facilitates discovery and its translation into a direct benefit to patients and the general public. A Comprehensive Cancer Center demonstrates depth and breadth of research in basic laboratory, clinical, and population sciences, and has substantial achievements in education and training of biomedical professionals and in addressing cancer issues specific to its location. NCI also recognizes and provides support for basic or clinical cancer centers depending on the whether the center pursues clinical research. Not all patients treated at these centers participate in research. Visit their website, cancercenters.cancer.gov, for a searchable list of the NCI-designated cancer centers.

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. Visit their website, **accc-cancer.org/membership_directory**, for a searchable directory of the member community centers by state.

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 Visit their website, **childrensoncologygroup.org**, for a listing of COG institutions by state.

Choosing among Recommended Treatments

Quality cancer treatment strives to both extend survival and maintain quality of life.[153] The goal is to select the treatment that will most effectively eliminate or slow the growth of 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. Patients and family may want to educate themselves about their treatment options

so they can be informed participants in treatment decisions. Helpful information is available online at **prepareforyourcare.org** to assist patients and families in communicating with each other and their care team. Visit **cancer.org/treatment** for a list of questions cancer survivors should ask when choosing among recommended treatments, along with treatment tools and other information.

In cases of advanced cancer where prognosis is poor and 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 circumstances, conversations among the patient, family, and clinicians about goals of care, advanced care planning, and hospice can be very helpful. Preferably, this conversation should begin before the patient is too ill to participate. See "Palliative Care" on page 24 for more information.

Cancer Disparities and Barriers to Treatment

Quality cancer care can significantly increase survival and quality of life during and after treatment. However, state-of-the art cancer treatments are not available across all segments of the population. Consequently, disparities in cancer treatment and outcomes persist for medically underserved populations such as racial and ethnic minority groups, the uninsured or underinsured, rural populations, and the elderly.

The availability and quality of cancer care is influenced by structural barriers, as well as provider and patient factors. Structural barriers include inadequate health insurance, complexities of the health care system, treatment facility hours of operation, appointment wait times, and access to transportation. Physician factors include attitudes, beliefs, preferences, and implicit or explicit biases influencing treatment delivery and recommendations. Patient decision making may be influenced by attitudes and beliefs about specific treatments, life circumstances and competing demands, health literacy, and perceptions about the health care system. The relative influence of structural, provider, and patient factors is not well understood; however, consistent evidence indicates inadequate health insurance is an important barrier to receiving timely and appropriate care.[154, 155]

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.[156] Cancer survivors younger than age 65 experience the most financial hardship.[157] Not all cancer specialists or facilities may be included in an insurance plan's network; thus, it is important to confirm coverage before treatment begins. People shopping for new health insurance should evaluate coverage for cancer treatment because 1 in 2 men and 1 in 3 women will develop cancer. The American Cancer Society and its nonprofit, nonpartisan advocacy affiliate, the American Cancer Society Cancer Action Network℠ (ACS CAN), have developed a worksheet to help people compare insurance plan coverage. Visit **acscan.org/healthcare/learn** to download a copy.

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. Newly diagnosed cancer patients can enroll in Medicaid if they meet income guidelines in their state, though these income guidelines may be very low, depending on the state.

The implementation of the Affordable Care Act (ACA) helped to alleviate some of the burden of cancer for patients and families. For example, the ACA prevents health insurers from excluding coverage based on preexisting conditions, including cancer. The ACA also 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, not all states have chosen to expand Medicaid coverage, so monitoring and assessing the effects of the ACA on health care access and disparities will be essential.[158]

Impairment-driven Cancer Rehabilitation

Physical and mental impairment because of preexisting medical problems, the cancer itself, or cancer treatment may significantly reduce survivors' ability to function, resulting in disability and poor quality of life. Examples of impairments include muscular weakness or paralysis, swallowing or speech problems, lymphedema, 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.[30] Impairment-driven cancer rehabilitation 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 who specialize in rehabilitation medicine) and physical, occupational, and speech therapists. It is very common for survivors to have multiple impairments that should be treated with an interdisciplinary rehabilitation approach. For some patients, providing "pre-habilitation," or targeted interventions delivered before treatment onset to improve physical and emotional recovery, may also be appropriate.[29]

Palliative Care

The focus of palliative care is to alleviate symptoms associated with cancer and its treatment, such as pain, other physical symptoms, and emotional distress.[159] Palliative care improves quality of life for cancer patients and their families and has also been shown to improve survival.[160, 161] It is appropriate at any stage of cancer diagnosis and not only for those with advanced disease, 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 team may include specially trained doctors, nurses, chaplains/spiritual counselors, social workers, and others. 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 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, nonpartisan advocacy affiliate, the American Cancer Society Cancer Action Network (ACS CAN), is working to improve access to palliative care for all adults and children facing cancer and other serious illnesses. Visit **acscan.org/qualityoflife** and **patientqualityoflife.org** for more information. Visit the American Cancer Society website at **cancer.org/treatment/treatmentsandsideeffects/palliativecare** and **getpalliativecare.org** to learn more about palliative care or find palliative care professionals.

The Recovery Phase

After primary treatment ends, most cancer patients transition to the recovery phase of survivorship. Challenges during this time may include dealing with the lingering effects of illness and treatment (e.g., fatigue, pain, bowel or bladder changes, sexual dysfunction), 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 various health care needs. Moreover, family and friends who provided support during treatment typically return to more normal levels of engagement and the frequency of meetings with the cancer care team generally declines.

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 Committee on Cancer Survivorship published a report highlighting the need for a strategy to improve the coordination of ongoing care for survivors.[162] 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.[163] The comprehensive treatment summary, which provides a foundation for the plan, contains the following personalized, detailed information:[164, 165]

- 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)
- Complications (side effects of treatment, hospitalizations, etc.)
- Supplemental therapy (e.g., physical therapy, adjuvant therapy, such as tamoxifen)

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
- Actions that can be taken to address persistent treatment-related problems
- 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.[166] 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 its production.[167] As a result, many survivors do not receive this information. One nationally representative study found that only 20% of oncologists consistently provided survivorship care plans to colorectal and breast cancer patients.[168] The implementation of these plans could be facilitated by the development of consensus guidelines for the content that should be included in them, as well as the use of electronic systems to reduce the time required to individually tailor the plans.[169]

Long-term Survivorship

Long-term survivorship can be both stressful and hopeful. Survivors are remarkably resilient, 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. The American Cancer Society has begun to issue evidence- and consensus-based comprehensive survivorship care guidelines to aid primary care and other clinicians in addressing these and other concerns in adult survivorship care. (For more information, see page 31.)[65,89,170,171]

Quality of Life

Quality of life is a broad multidimensional concept that considers a person's physical, emotional, social, and spiritual well-being. According to data from the National Health Interview Survey, approximately 1 in 4 cancer survivors reports a decreased quality of life due to physical problems and 1 in 10 due to emotional problems.[172] 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.

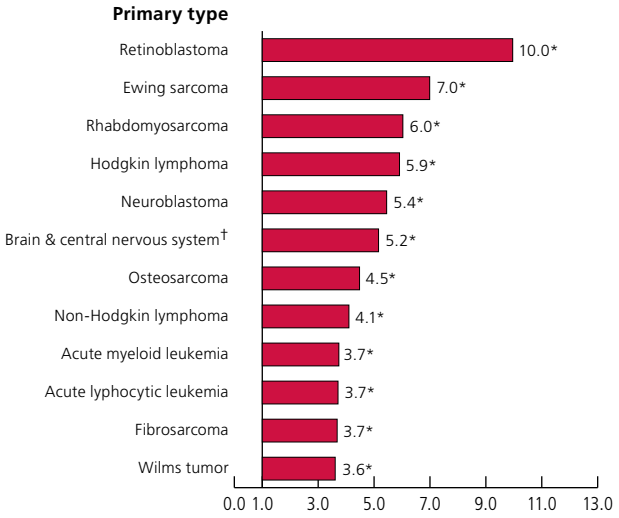
Among long-term cancer survivors (5 years or more), emotional well-being is comparable to that of those with no history of cancer, while a significant number report lower overall physical well-being than their peers.[172, 173] Individuals who have a history of more invasive and aggressive treatments tend to report poorer functioning and quality of life in the long term. In addition, certain groups of survivors, such as racial/ethnic minorities and those of lower socioeconomic status, also report greater difficulty regaining quality of life.[174,175] 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.[176] In addition, survivors diagnosed at a younger age tend to have poorer emotional functioning, whereas older age at diagnosis is often associated with poorer physical functioning.[177, 178]

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.[78]

Risk of Recurrence and Subsequent Cancers

Fear of cancer recurrence is one of the most common concerns of posttreatment cancer survivors.[179] Cancer survivors are at risk for recurrence of the original cancer and the development of new primary cancers. Even after treatment appears to have been effective, cancer cells may persist and grow to the point where they are detected – this is called recurrence. Recurrence can occur near the site of the original cancer (local recurrence), in lymph nodes near the original site (regional recurrence), or elsewhere in the body (distant recurrence or metastasis). Although national estimates of recurrence are not available because data on recurrence are not collected by cancer registries, studies show that recurrence rates vary depending on tumor characteristics, stage of disease, and treatments received. For some types

Figure 15. Observed-to-expected (O/E) Ratios for Subsequent Cancers by Primary Type, Ages 0-19, 1975-2012



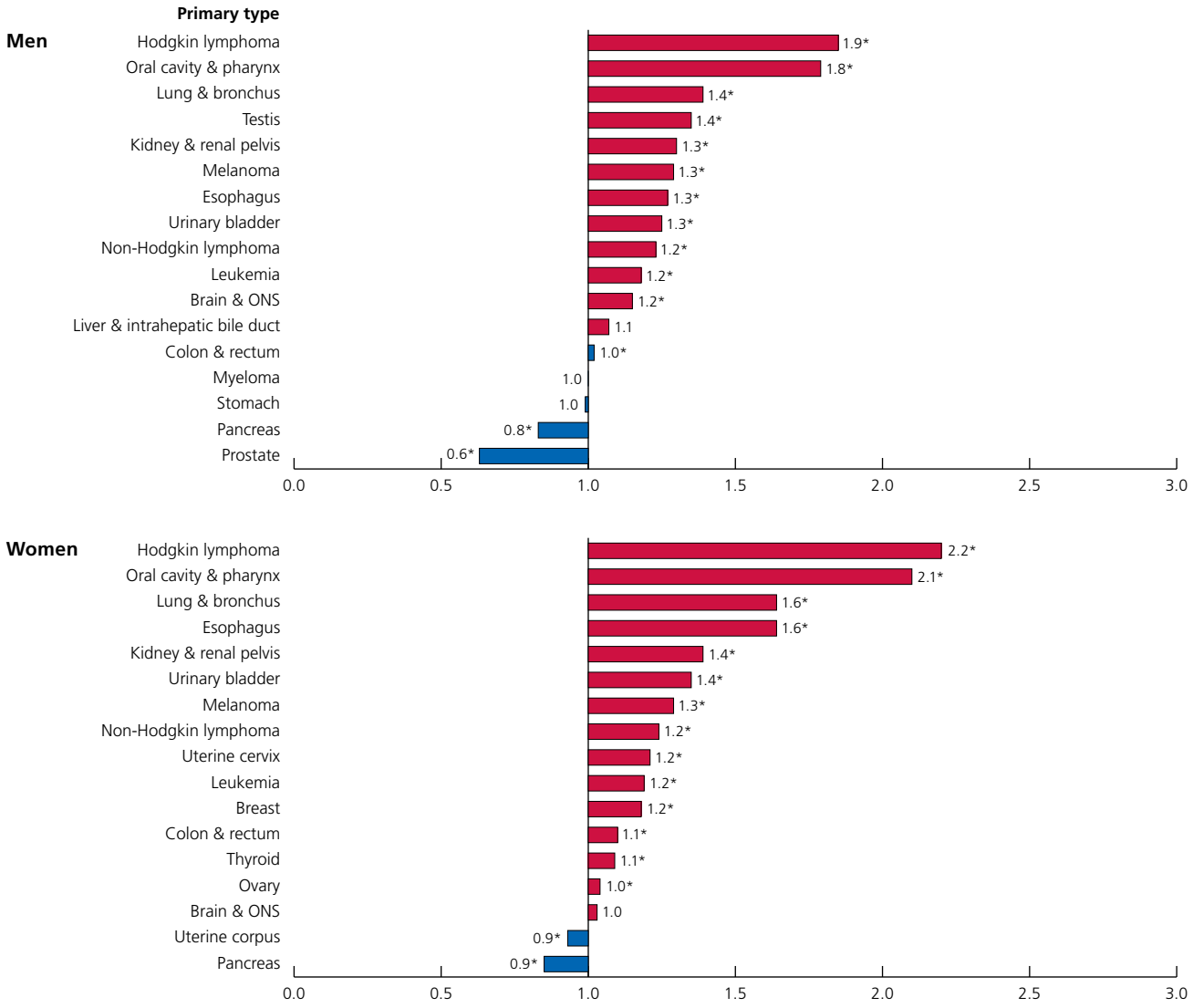
*The ratio of the number of subsequent cancers observed among cancer survivors to the number of cancers expected is statistically significant ($p<0.05$).
†Excludes benign and borderline brain tumors.

Note: Observed-to-expected ratio is the number of cancers that were observed among cancer survivors in the SEER 9 areas, divided by the number of cancers expected in this population, calculated using the population-based age-specific incidence rates in the SEER 9 areas.

Source: Surveillance Epidemiology, and End Results (SEER) Program, 9 SEER Registries, National Cancer Institute.[96]

American Cancer Society, Surveillance and Health Services Research, 2016

Figure 16. Observed-to-expected (O/E) Ratios for Subsequent Cancers by Primary Type and Sex, Ages 20 and Older, 1975-2012



*The ratio of the number of subsequent cancers observed among cancer survivors to the number of cancers expected is statistically significant ($p<0.05$).

Note: Observed-to-expected ratio is the number of cancers that were observed among cancer survivors in the SEER 9 areas, divided by the number of cancers expected in this population, calculated using the population-based age-specific incidence rates in the SEER 9 areas.

Source: Surveillance, Epidemiology, and End Results (SEER) Program, 9 SEER registries, National Cancer Institute.[96]

American Cancer Society, Surveillance and Health Services Research, 2016

of cancer, such as prostate, there are formulas that can help estimate the chance of recurrence based on stage and other clinical information.[180]

A second (or multiple) primary cancer is a new cancer that is biologically distinct from the original cancer. Whether a cancer is a new primary or a recurrence is important because it determines prognosis and treatment. The risk of developing a second primary cancer varies by the type of cancer first diagnosed (referred to as the first primary), treatment received, age at diagnosis, and other factors. Ratios of the observed-to-expected number of cancer cases (O/E) among cancer survivors in population-based cancer registries are used to describe the risk for a subsequent cancer diagnosis, with the number expected based on cancer occurrence in the general population. As a whole, cancer survivors have a small increased risk of additional cancers, although risk is higher for those with a history of childhood cancer (Figure 15, page 25), as well as for adult survivors of Hodgkin lymphoma and tobacco-related cancers (oral cavity and pharynx, lung and bronchus, kidney and renal pelvis, esophagus, and urinary bladder) (Figure 16). For example, female survivors of Hodgkin lymphoma treated with radiation to the chest are at

particularly increased risk of developing breast cancer. In addition to the carcinogenic effects of cancer treatment and shared risk factors, genetic susceptibility also influences risk.[181]

The American Cancer Society's survivorship care guidelines include recommendations for clinicians regarding appropriate surveillance for recurrent and new primary cancers. [65,89,170,171] Cancer survivors who have completed treatment should ask their provider about the appropriate timing and types of follow-up tests recommended to look for recurrent or new cancer. Health strategies to reduce the risk of recurrence and additional cancers, as well as improve survivor health and quality of life, are provided in the next section.

Regaining and Improving Health through Healthy Behaviors

Healthy behaviors are especially important for cancer survivors. For example, posttreatment physical activity has been associated with increased recurrence-free and overall survival for some cancers, whereas overweight and obesity have been consistently associated with poorer survival for many cancers.[182-186] Smoking after treatment increases the risk of recurrence for lung cancer survivors, as well as the occurrence of additional smoking-related cancers.[187, 188] In addition, healthy behaviors may also improve survivor functioning and quality of life.[189] Clinical trials demonstrate that exercise can improve heart and lung function and reduce cancer-related fatigue among survivors.[190, 191] The growing evidence that health behaviors are beneficial to survivors led the American Cancer Society to develop a guideline for physical activity and nutrition for cancer survivors during and after treatment.[192] Since these guidelines were originally released, a number of practical interventions for survivors addressing diet, weight, and physical activity have been developed and tested.[193]

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 for some cancers.[190] 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%).[194] Similar benefits have been observed among colon cancer survivors.[195] Intervention studies have shown that exercise can improve fatigue, anxiety, depression, self-esteem, happiness, and quality of life in cancer survivors.[190]

Exercise recommendations for cancer survivors should be tailored to 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), financial, or structural (e.g., unfavorable community environments).[195] Physical impairments should be assessed by rehabilitation professionals before general exercise recommendations are made.[30]

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).[196] 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.[197] Obesity may also increase the risk of some treatment-related side effects, such as lymphedema and fatigue.[198]

A diet that is plentiful in fruit, vegetables, and whole grains with 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.[199] In addition, alcohol consumption has been linked to cancers of the mouth, pharynx, larynx, esophagus, liver, colorectum, and female breast, and possibly pancreas. 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).[197] Head and neck cancer survivors should be advised, based on their individual clinical and prognostic factors, about alcohol consumption due to their risk of developing a second cancer and risk of adverse alcohol-related effects.[171]

Smoking cessation. A significant number of cancer survivors, particularly those who are young, continue to smoke after their diagnosis. From 2003 to 2012, 35% of cancer survivors ages 18 to 44 were current smokers compared to 23% of those in the general population,[200] despite the fact that smoking interferes with some common cancer treatments and increases the risk for 12 different cancer types, heart disease, and many other chronic health conditions.[201] Studies have shown that smoking cessation efforts are most successful when they are initiated soon after diagnosis.[202] Follow-up support for survivors who quit, and for those who are not initially successful, is also needed as recent research has found that even up to 9 years after diagnosis, almost 10% of survivors were still smoking.[203] Increasing survivors' access to cessation aids, developing tailored interventions, and health systems' use of the 5 A's (Ask, Advise, Assess, Assist, Arrange) is likely to reduce smoking among cancer survivors. For more information on Society resources for smoking cessation, see page 31.

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.[204]

Concerns of Caregivers and Families

Cancer not only affects survivors but also their family members and close friends. According to the 2015 National Alliance for Caregiving and AARP Study Report, 7% of the general population is a family caregiver of a loved one with cancer.[205] 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.[206] Most caregivers are the spouse (66%) or offspring (18%) of cancer patients, and caregivers are more likely to be women (65%) than men.[207]

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 cancer diagnosis, caregivers were still spending an average of 8 hours per day providing care, with the highest time costs associated with providing care for lung cancer patients.[208]

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.[209] A recent study showed that stressed caregivers were more likely to develop heart disease, and spousal caregivers were more likely than other caregivers to develop arthritis and chronic back pain several years after the initial caregiving experience.[210] Caregivers are also 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.[211] 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.[212-214] Consultation with palliative care teams has also been shown to help ease family caregiver burdens. (See "Palliative Care" on page 24 for more information.) A recent systematic review suggested that caregivers benefit most from problem-solving and communication skills interventions.[214] Newer web-based interventions have also shown promising results in reducing caregiver burden and improving mood.[213]

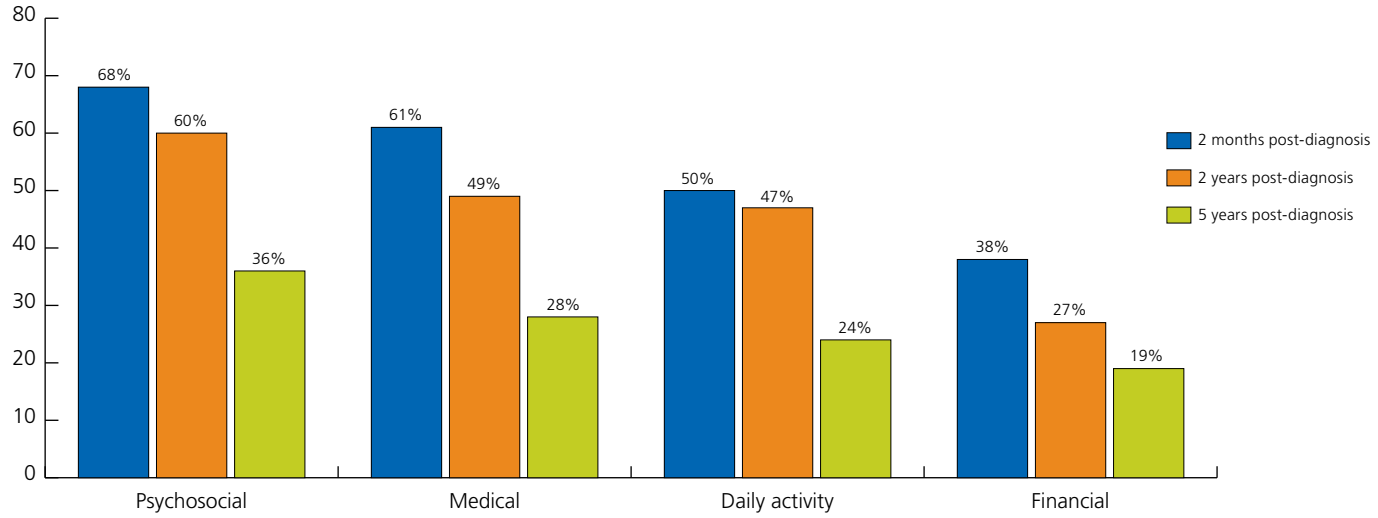
A cancer diagnosis is often seen as a "teachable moment" for both survivors and caregivers, wherein the illness experience becomes a catalyst for behavior change and sustainable lifestyle benefits.[215] Increasing evidence has shown that caregivers may also be motivated to make positive changes to improve their own health after a loved one's cancer diagnosis.[216] 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 uncertainty about the future and concerns about recurrence are lingering issues for caregivers, particularly those caring for survivors diagnosed at a more advanced stage or with a type of cancer more likely to be fatal.[217,218] 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.[219]

Caregivers report a variety of persistent unmet needs (Figure 17).[220] Caregivers' psychosocial needs are primarily centered on their ability to help the cancer survivor deal with their emotional distress and to 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 prevalent 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 posttraumatic 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.[221, 222] 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.

Figure 17. Caregivers' Unmet Needs across the Cancer Trajectory



Source: Kim, et al.[220] Reprinted from *Psychooncology* 2010; 19(6):573-582. This material is reproduced with the permission of John Wiley & Sons, Inc.

The American Cancer Society

How the American Cancer Society Saves Lives

The American Cancer Society is an organization of 2.5 million strong. From prevention to diagnosis, from treatment to recovery, we're here every step of the way.

Prevention and Early Detection

The American Cancer Society is doing everything in our power to prevent cancer. We are diligent in encouraging cancer screenings for early detection and promoting healthy lifestyles by bringing attention to obesity, healthy diets, physical activity, and avoiding tobacco. 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 more than 200 languages.

Information on every aspect of the cancer experience, from prevention through survivorship, is also available through cancer.org, the Society's website. 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. Visit cancer.org/bookstore for a complete list of Society books that can be ordered.

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*. Visit cancer.org/cancer/bookstore/medicalandclinical-journals/index for more information about subscriptions and online access to these 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 is 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 more than 120 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 2014, 56,000 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. For cancer patients, getting to and from treatment may be one of their toughest challenges. The American Cancer Society Road To Recovery program provides free rides to cancer patients to and from treatments and cancer-related appointments. Trained volunteer drivers donate their time and the use of their personal vehicles to help patients get to the treatments they need. In 2014, the American Cancer Society provided more than 341,000 rides to cancer patients.

Lodging during treatment. The American Cancer Society Hope Lodge® program provides free overnight lodging to patients and their caregivers who have to travel away from home for treatment. Not having to worry about where to stay or how to pay for it allows patients to focus on what's important: getting well. In 2014, the 31 Hope Lodge locations provided more than 276,000 nights of free lodging to 44,000 patients and caregivers – saving them $36 million in hotel expenses. Through its Hotel Partners Program, the Society also partners with local hotels across the country to provide free or discounted lodging to patients and their caregivers in communities without 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 posttreatment 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 the National Cancer Survivorship Resource Center to address the needs of adult posttreatment cancer survivors. Survivorship care plans give cancer survivors an overview of the care they have received and prioritize areas for follow-up as they transition from a continuous care setting to recovery at home. Visit cancer.org/survivorshipcareplans to find tools to help create survivorship care plans.

Breast cancer support. Through the American Cancer Society Reach To Recovery® program, trained breast cancer survivor volunteers are matched to people facing or living with breast cancer. Program volunteers give cancer patients and their family members the opportunity to ask questions, talk about their fears and concerns, and express their feelings. The Reach To Recovery volunteers have been there, and they offer understanding, support, and hope. In 2014, the program assisted nearly 8,000 patients

Cancer education classes. The I Can Cope® online educational program is available free to people facing cancer and their families and friends. The program consists of self-paced classes that can be taken anytime, day or night. People are welcome to take as few or as many classes as they like. Among the topics offered are information about cancer, managing treatments and side effects, healthy eating during and after treatment, communicating with family and friends, finding resources, and more. Visit cancer.org/icancope to learn more about the classes that are available.

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*® publication offers affordable hair loss and mastectomy products, as well as advice on how to use those products. The *"tlc"*™ products and catalogs may be ordered 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.

National Cancer Survivorship Resource Center

The National Cancer Survivorship Resource Center (The Survivorship Center) is a collaboration between the American Cancer Society, the George Washington University Cancer Institute, and the Centers for Disease Control and Prevention, funded by the Centers for Disease Control and Prevention. Its goal is to shape the future of posttreatment 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 the policy and advocacy community.

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 includes trusted resources for survivorship information and tips on how to communicate with health care providers. Visit **cancer.org/survivorshipguide** for a copy of the guide.

Tools for health care professionals

Adult Posttreatment Cancer Survivorship Care Guidelines – a series of guidelines developed to assist primary care providers and other clinicians as they provide long-term, clinical follow-up care for cancer survivors, including surveillance for recurrence, screening for new cancers, management of chronic and late effects, support for health behavior changes, and referrals for rehabilitation, psychosocial, and palliative care needs or other specialty care. Guidelines for survivors of prostate, female breast, colorectal, and head and neck cancers have been released.[65,89,170,171] (Visit **cancer.org/professionals** for copies of the guidelines.)[65, 89] An overview of this ongoing work, available at **bit.ly/SurvivorshipCenter**, was previously published.[223] A toolkit that includes resources to help clinicians implement these guidelines, along with information about provider training opportunities and patient materials, is also available. (Visit **bit.ly/NCSRCToolkit** for copies of the toolkit.)

A Cancer Survivor's Prescription for Finding 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 phone. Visit **cancer.org/survivorshipprescription** for a copy of the tool.

Moving Beyond Patient Satisfaction: Tips to Measure Program Impact Guide – a brief guide that details indicators and outcome measures that can be used to monitor the success of survivorship programs. Visit **cancer.org/survivorshipprogramevaluation** for a copy.

Guide for Delivering Survivorship Care – a guide that provides health care professionals with the knowledge, tools, and resources to deliver high-quality cancer survivorship care to cancer survivors. Visit **smhs.gwu.edu/gwci/survivorship/ncsrc/guidequalitycare** for a copy.

Cancer Survivorship E-Learning Series for Primary Care Providers – a free online continuing education program designed to educate primary care providers on the care needs of cancer survivors, and on the cancer survivorship care guidelines to help them provide clinical follow-up care for cancer survivors. Visit **cancersurvivorshipcentereducation.org** to access the series online.

Smartphone App for Clinicians – a free mobile app is in development to house content from the breast, colorectal, head and neck, and prostate cancer survivorship care guidelines. The app will make this content available for clinicians as a tool for use in the clinical encounter. Anticipated release is spring 2016.

Tools for cancer advocates and policy makers

Cancer Survivorship: A Policy Landscape Analysis – a white paper designed to educate policy makers on survivorship issues and describe the priority areas for improving cancer survivorship care. Visit **cancer.org/survivorshippolicypapers** for a copy of the paper.

Visit **cancer.org/survivorshipcenter** to learn more about The Survivorship Center activities.

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 with cancer manage the appearance-related side effects of treatment. The free program engages certified, licensed beauty professionals trained as Look Good Feel Better volunteers to teach simple techniques on skin care, makeup, and nail care, and give practical tips on hair loss, wigs, and head coverings. Information and materials are also available for men and teens. To learn more, visit the Look Good Feel Better website 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. The American Cancer Society Cancer Survivors Network® is a free online community created by and for people living with cancer and their families. At **csn.cancer.org**, they can get and give support, connect with others, find resources, and tell their own story through personal expressions like music and art.

Smoking cessation. The Quit For Life® Program is the nation's leading tobacco cessation program, offered by 27 states and more than 700 employers and health plans throughout the US. A collaboration between the American Cancer Society and Optum,

the program is built on the organizations' more than 35 years of combined experience in tobacco cessation. The Quit For Life Program employs an evidence-based combination of physical, psychological, and behavioral strategies to enable participants to take responsibility for and overcome their addiction to tobacco. A critical mix of medication support, phone-based cognitive behavioral coaching, text messaging, web-based learning, and support tools produces an average 6-month quit rate of 49%.

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 communities. 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. 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

The 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. The 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.

Research

Research is at the heart of the American Cancer Society's mission. For 70 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 anticancer organization to put answers into action.

As of February 3, 2016, the Society is funding approximately $66 million in cancer treatment research and more than $91million in cancer control, survivorship, and outcomes research. The Society has awarded 83 grants in symptom management, and palliative care focused on patient, survivor, and quality of life research. Of those, 42 grants were funded through a partnership with the National Palliative Care Research Center over the past 10 years, with five new grantees added in 2015.

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 though the Society's ongoing nationwide studies of cancer survivors
- Examining differences in receipt of treatment by race/ethnicity and insurance status in the National Cancer Data Base

- Examining how sleep disturbance and a history of depression in breast cancer survivors may make one more vulnerable to accelerated aging
- Developing an electronic decision aid to present information about acute myeloid leukemia (AML) and treatment options and testing the effect of this new decision aid on AML patients
- Testing a program to provide education, skills training, and support to advanced LC patients and their families shortly after diagnosis
- Developing a pain management intervention for colorectal cancer survivors that addresses both pain and psychological distress
- Developing a spiritually sensitive palliative care intervention that will lead to more and better palliative care for Muslims
- Evaluating the potential effect of five FDA-approved CYP inhibitors on TRPV1-active lipids released from oral cancer cells, offering a unique opportunity to help control oral cancer pain and improve the quality of life of cancer patients
- Examining whether cordotomy can reduce pain intensity in patients with refractory cancer pain in patients who have been medically optimized by a multidisciplinary supportive care team
- Developing a health measurement survey instrument that can measure quality of life in lung cancer patients for clinical comparison studies and also can be used for economic analysis
- Evaluating the prevalence, determinants, and consequences of difficult relationships between parents and physicians, in order to identify avenues to improve care for children whose parents and physicians are engaged in difficult relationships
- Using Acceptance and Commitment Therapy (ACT) to reduce anxiety and increase vitality in cancer survivors, and identifying active therapeutic processes that predict ACT outcomes

Advocacy

Conquering cancer is as much a matter of public policy as scientific discovery. Whether it's advocating for quality care, affordable health care for all Americans, increasing funding for cancer research and programs, or enacting laws and policies that help decrease tobacco use, policy makers 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 potentially lifesaving screenings and treatment, 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
  - Creates health insurance marketplaces in every state where individuals can shop online for health insurance and compare health plans
  - Helps people and families with low to moderate incomes buy health insurance
  - Requires all health plans sold in new health insurance marketplaces to cover essential health benefits that include cancer screening, treatment, and follow-up care
  - Makes coverage for routine care costs available to patients who take part in clinical trials
  - Makes proven cancer screenings and other preventive care available at no cost to people in new plans, in Medicare, or who are newly eligible for Medicare
  - 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
  - Provides funding to states that choose to expand Medicaid coverage to low-income adults (below 133% of the federal poverty level)
  - Enhances data collection and reporting to ensure racial and ethnic minorities are receiving appropriate, timely, and quality health care

  - 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. ACS CAN has:
  - 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 quality-of-life legislative platform that addresses the needs for better patient access to palliative care services and calls for expanded research funding and an increased health professions workforce to provide patients with serious illnesses better patient-centered, coordinated care

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. ACS CAN's 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. ACS CAN's advocacy initiatives and the Society's targeted research programs 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

ACS CAN's 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 for what's right. ACS CAN and the Society are also championing the cancer community through our Relay For Life® and Making Strides Against Breast Cancer® programs. The Relay For Life movement is the world's largest grassroots fundraising event to end every cancer in every community. Rallying the passion of four million people worldwide, Relay For Life events raise critical funds that help fuel the mission of the Society, an organization whose reach touches so many lives – those who are currently battling cancer, those who may face a diagnosis in the future, and those who may avoid a diagnosis altogether thanks to education, prevention, and early detection. The Making Strides Against Breast Cancer walk is a powerful event to raise awareness and funds to end breast cancer. It is the largest network of breast cancer events in the nation, uniting nearly 300 communities to finish the fight. The walks raise critical funds that enable the Society to fund groundbreaking breast cancer research; provide free comprehensive information and services to patients, survivors, and caregivers; and ensure access to mammograms for women who need them so more lives are saved.

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.[224] Incidence and survival were modeled by cancer type, sex, and age group using malignant cancer cases diagnosed during 1975-2012 from the nine oldest registries in the Surveillance, Epidemiology, and End Results (SEER) program (2014 data submission). Incident cases included the first diagnosed cancer for a specific cancer type from 1975 to 2012. This differs from previous prevalence projections, which only included the first malignant tumor ever recorded for a survivor. Mortality data for 1975 to 2012 were obtained from the National Center for Health Statistics. Population projections for 2014 to 2026 were obtained from the US Bureau of Census. Projected US incidence and mortality for 2013 to 2026 were calculated by applying 5-year average rates (2008-2012) to the respective US population projections by age, sex, race and year. Survival, incidence, and all causes mortality were assumed to be constant from 2013 through 2026. These projections reflect the impact of the aging and increase of the US population. For more information on this method, please see publications by Mariotto et al.[225, 226]

New cancer cases. The number of new cancer cases in the US in 2016 was published previously.[116] The estimates were calculated using a spatiotemporal model based on incidence data from 49 states and the District of Columbia for 1998 to 2012 that met the North American Association of Central Cancer Registries' 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 1975-2012*.[57] Current survival estimates are based on cases diagnosed during 2005 to 2011 and followed through 2012 from the 18 SEER registries. 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 8.2.1.[96, 227] One-year survival rates are based on cancer patients diagnosed from 2009 to 2011, 10-year survival rates are based on diagnoses from 1999 to 2011, and 15-year survival rates are based on diagnoses from 1994 to 2011; all patients were followed through 2012.

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 1,500 facilities accredited by the American College of Surgeons' Commission on Cancer (CoC). The NCDB contains standardized data regarding patient demographics, cancer type, and staging, as well as first course of treatment. Unlike population-based registries, the NCDB also collects treatment information on chemotherapy, targeted drugs, and immunotherapy. However, because these therapies may not be classified in the same way from year to year, this report combines these treatments into a single chemotherapy category. Visit the SEER-Rx website, seer.cancer.gov/tools/seerrx, for further information regarding the classification of anti-cancer drugs into the categories of chemotherapy, immunotherapy, hormonal therapy, and targeted therapy. 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.[228] Additionally, cancers that are commonly treated and diagnosed in non-hospital settings (e.g., melanoma, prostate cancer, and nonmuscle invasive bladder cancer) are less likely to be captured by the NCDB because it is a hospital-based registry. Visit facs.org/cancer/ncdb for more information about the NCDB.

SEER-Medicare Database. The SEER-Medicare-linked database is a large integrated population-based cancer registry and claims dataset. It 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 ages 65 years and older. Medicare data include 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. Visit their website, appliedresearch.cancer.gov/seermedicare/, for more information on the SEER-Medicare database.

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Acknowledgments

The production of this report would not have been possible without the efforts of: Kassandra Alcaraz, PhD, MPH; Catherine Alfano, PhD; Rick Alteri, MD; Tracie Bertaut, APR; Durado Brooks, MD, MPH; Keysha Brooks-Coley; Rachel Spillers Cannady; Karim Chamie, MD, MSHS; Ellen Chang, ScD; Carol DeSantis, MPH; Nicole Erb; Christopher Flowers, MD; Rachel Freedman, MD, MPH; Ted Gansler, MD, MBA, MPH; Phillip Gray, MD; Anna Howard; Joan Kramer, MD; Chun Chieh Lin, PhD, MBA; Alex Little, MD; Angela Mariotto, PhD; Anthony Piercy; Cheri Richards, MS; Julia Rowland, PhD; Debbie Saslow, PhD; Julie Silver, MD; Jennifer Singleterry, MA; Scott Simpson; Tenbroeck Smith, MA; Kevin Stein, PhD; Dana Wagner; Elizabeth Ward, PhD.

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