Issues in Focus

The Patient Voice Across the Cancer Care Continuum

Screening, Diagnosis, and Prehabilitation

Genentech
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Disclosure

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The Patient Voice Across the Cancer Care Continuum
Screening, Diagnosis, and Prehabilitation

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Suggested Citation


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In Memoriam

This edition is dedicated to the memory of Jan Gbur who served as Emron’s project manager for this report. Her voice was silenced by a short battle with cancer. She is missed and fondly remembered.
Introduction

Many Americans know all too well the devastation cancer can bring. Cancer spans all ages from children to adolescents/young adults, working-age adults, retired adults, and the frail elderly—and affects people across the socioeconomic spectrum and from all ethnicities and cultures. The American Cancer Society estimates that nearly 1.7 million new cancer cases will be diagnosed in the United States in 2016, and that more than 595,000 Americans will die from some form of the disease.

The patient experience with cancer is at the forefront of the public eye, especially with a new, national “Moonshot” initiative to eliminate cancer instituted in 2016. This $1 billion initiative will focus on making the most of federal investments, targeted incentives, private-sector efforts from industry and philanthropy, patient-engagement initiatives, and other mechanisms to accelerate the development of new cancer detection methods and treatments.

CANCER PATIENTS BY THE NUMBERS\textsuperscript{1,2}

- **1,685,210** Estimated new cases of cancer in 2016
- **23%** Drop in cancer death rate from 1991 to 2012 due to smoking reduction and improved early detection and treatment
- **Nearly 14.5 million** Number of cancer survivors in 2014

CANCER SURVIVORS LEND THEIR VOICES

Leaders representing a diverse group of stakeholders from across the United States came together at Genentech’s corporate campus in South San Francisco, California, to attend the 2016 Genentech Oncology Institute on May 4–5, 2016.\textsuperscript{4} This year’s program focused on the cancer patient journey through prevention, diagnosis, treatment decisions, and outcomes. Cancer survivors shared their experiences through video vignettes during the event. Commentary from these vignettes regarding the following survivors are included in this report.

**Cancer survivor profiles**

- **Mia is a 47-year-old breast cancer survivor**
  - She describes herself as being healthy and active and following a vegan diet. She started dancing at the age of 5 and has been a fitness instructor for over 30 years. With a strong family history of breast cancer, Mia shares her thoughts about proactive breast cancer screening and patient decision making.
- **Glenn is a 63-year-old chronic lymphocytic leukemia (CLL) survivor**
  - He describes himself as a significantly overweight couch potato until the age of 47 when he took up and became addicted to running. He was diagnosed with CLL as a result of a routine physical exam. After receiving his diagnosis on the telephone, Glenn shares his experience with gathering timely information from Web sites and chat rooms.
- **Jose is a 55-year-old lung cancer survivor**
  - He speaks about his emotional struggles, concerns about his job and ability to work, and what he has learned from other cancer survivors.
- **Jennifer is a 31-year-old ovarian cancer survivor**
  - She was diagnosed with ovarian cancer at age 17 during a pregnancy. She speaks about her trust in her doctors, fears of seeming weak, and the need to be strong for her family.
Due to the nature of the disease, cancer’s influence is far reaching and often calls upon the support of family members as unpaid caregivers. The experience of cancer can also strain or negatively impact patients’ socioeconomic status due to the financial burden of cancer treatments, loss of work, and long-term consequences of cancer. In addition, the physical and psychosocial effects of cancer may linger long after active treatment ends.

A 20% improvement in the 5-year relative survival rate for all cancers from 49% in 1975 to 69% in 2011 means that more people are living with cancer as a chronic disease. Survival is improving due to advanced diagnostics, less toxic and more targeted therapies, the availability of second- or even third-line therapies, and improved surgical and radiation therapy techniques.

Cancer is a complicated disease steeped in complex terminology, and having cancer is not like having any other kind of illness. Cancer is an experience that only those who have had cancer seem to truly understand; yet, people do not have uniform or parallel responses to having cancer. A cancer patient’s needs and experience change dramatically over the course of cancer care, and best practices for addressing these needs vary significantly across the patient journey.

In order to provide quality of care and life, it is important to understand the attitudes, aptitudes, needs, and experiences of cancer patients so that providers can effectively communicate with them, seek their involvement in decision making and goal setting, and support living with cancer.
Cancer screening — testing individuals for a particular cancer when they are asymptomatic — reduces mortality from numerous cancers, such as colon and rectal, breast, uterine, cervix, and lung. According to the American Cancer Society, when colorectal cancer is found at an early stage before it has spread, the 5-year relative survival rate is about 90%. However, only about four out of 10 colorectal cancers are found at this early stage, emphasizing the need for regular screening. When cancer has spread outside the colon or rectum, survival rates are lower.

Cancer screening guidelines and recommendations must carefully balance the benefits from screening with the uncertainties and risks that certain screenings present (see box). Reducing the overuse of services, including screening, where harms outweigh benefits is a growing concern to professional societies and health care at large.

Most guidelines now take into account the importance of patient preferences, and the move toward a policy of shared decision making has helped mitigate controversy in this arena and is promoting an emerging consensus around a patient-centered approach.

In a recent population-based Internet survey of adults aged 40 years and over, most respondents considered themselves well informed about cancer screening, though only about 50% answered the knowledge questions correctly. The majority markedly overestimated their lifetime risk of cancer diagnoses and mortality. Participants rated health care providers as the most important source of information.

The Affordable Care Act (ACA) eliminated patient cost sharing for evidence-based preventive care, yet the implementation of this policy by a large national insurer did not result in substantially higher utilization of colonoscopy and mammography. In addition, the ACA eliminated the Medicare Part B deductible and coinsurance requirements for routine colonoscopy screening tests, but Medicare continues to require beneficiaries to bear a portion of the cost when their screening colonoscopies are deemed diagnostic in nature, such as when a polyp is removed or a colonoscopy is performed following a positive fecal occult blood test. This distinction exposes Medicare beneficiaries to unexpected cost sharing and creates cost barriers to the receipt of this potentially lifesaving test.

**Challenges in cancer screening**

Inadequate cancer screening occurs more commonly in certain segments of the population.
Racial, ethnic, and cultural differences
Socioeconomic status and race or ethnicity account for marked disparities in access to cancer screening tests, making detection of cancer less likely and leading to increased cancer mortality among racial minorities.\textsuperscript{15,19} For example, findings from focus groups with 29 Somali women who had immigrated to the United States indicated that there is considerable stigma surrounding a cancer diagnosis that leads to secrecy and shame. Both older and younger women expressed concerns about radiation from mammograms and the fear that mammograms cause cancer.\textsuperscript{20}

Evidence suggests that multistrategy interventions are most effective in boosting cancer screening rates among underserved populations. Given the disparities that exist among different ethnic and cultural backgrounds and socioeconomic levels, interventions to improve cancer prevention and early detection must accommodate different languages and cultural values and beliefs, using a multidisciplinary strategy to achieve awareness of the importance of screening.\textsuperscript{15}

Low health literacy
Health literacy among cancer patients has been recognized as a critical factor affecting the continuum of cancer care from participating in prevention and screening to understanding explanations of diagnoses and treatments.\textsuperscript{21}

Cancer screening in older adults
Many challenges complicate cancer screening discussions in older adults.\textsuperscript{22} Screening tests may pose a greater threat to health, and an older individual’s comorbid status may make treatment options untenable. Decisions about the appropriate types of screening should be based on\textsuperscript{22}:

- Patients’ functional level, comorbidities, life expectancy, and health trajectory
- Potential benefits and harms associated with screening
- Patients’ preferences, which may involve proxy decision makers, such as a spouse or child

One study conducted with older adults aged 50 to 84 years regarding overused prostate or colon cancer, osteoporosis, and cardiovascular disease screening found that many do not perceive there to be any harms from screening. If they did name harms from screening, they were associated with the screening test and not the possible risks after screening is completed.\textsuperscript{14}

\textbf{Definition}\textsuperscript{23} **Health literacy** is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.

\textbf{Types of Literacy}\textsuperscript{24}

- **Visual**
  - Interpret graphs, symbols, charts, diagrams, or visual data

- **Numeric**
  - Calculate or reason numerically

- **Scientific**
  - Understand the basics of how science and medicine work

- **Computer**
  - Use a computer to access and comprehend information

- **Information**
  - Apply relevant information when making decisions

- **Cultural**
  - Interpret and act on health information through the lens of dynamic characteristics shaped by collective beliefs, customs, and social identity
Conflicting cancer screening recommendations
When different organizations issue conflicting recommendations about when and how cancer screenings should occur, screening guidelines for certain cancers can lead to confusion and misunderstanding. One of the more scrutinized recommendations has been the US Preventive Service Task Force (USPSTF) revised guidelines for breast cancer screening. They recommend routine screening mammography to begin at age 50 and continue every 2 years, citing that it leads to the greatest reduction in breast cancer mortality in women who are between the ages of 50 and 74 years. This conflicts with a 2015 update by the American Cancer Society, which maintains that women should have the opportunity to begin annual screening between 40 and 44 years; however, women aged 45 to 54 years should be screened annually. Women 55 years and older should transition to biennial screening or have the opportunity to continue screening annually.

A study of women aged 39 to 49 years designed to evaluate acceptance of the USPSTF changes revealed that 88% of women overestimated their risk for breast cancer.

Participation in clinical genetic screening
The incorporation of genetic testing into clinical care provides clinicians and the public with additional insight into familial and individual predisposition to certain diseases, allowing them to take additional steps to reduce those risks. As new technologies for cancer screening and early detection become available to the public, multiple studies have suggested that people regard genomics and new genomic technologies in a positive light. Research shows a majority would be willing to use genetic testing to find predispositions to common, complex disorders.

Many women base their risk of breast cancer on family history. However, breast cancers resulting from familial or genetic predisposition are thought to account for only 15% to 20% of all diagnosed cases, which means that 80% to 85% of breast cancers occur in women with no family history of the disease. One study based on the 2005 National Health Interview Survey confirmed that breast cancer risk perception was very strongly associated with family history of breast cancer in any first-degree relative, with the most compelling results seen in those whose mother or mother and sister had breast cancer (Figure 1). Determination of risk may affect mammography screening.

## Figure 1. Family history of breast cancer and risk perception

<table>
<thead>
<tr>
<th>History of breast cancer in mother or mother and sister</th>
<th>No breast cancer history in family</th>
</tr>
</thead>
<tbody>
<tr>
<td>More likely to get breast cancer</td>
<td>More likely to get breast cancer</td>
</tr>
<tr>
<td>51.4%</td>
<td>51.3%</td>
</tr>
<tr>
<td>Less likely to get breast cancer</td>
<td>Less likely to get breast cancer</td>
</tr>
<tr>
<td>7.8%</td>
<td>11.0%</td>
</tr>
<tr>
<td>As likely to get breast cancer</td>
<td>As likely to get breast cancer</td>
</tr>
<tr>
<td>40.9%</td>
<td>37.5%</td>
</tr>
</tbody>
</table>
Differences in access to, use of, and response to genomic information exist along many regional, ethnic, and cultural lines. Genetic screening may not be as accessible to and understood by ethnic minorities and the medically underserved. For example, studies suggest that individuals from minority racial and ethnic groups have lower knowledge, misunderstandings, and negative attitudes about genetic testing. In a focus group study with Latinas, awareness of familial breast and ovarian cancer and availability of genetic services were low, but after participants received information, they held favorable attitudes toward genetic services.

Genomics and personalized medicine

Cancer care providers today increasingly may rely on comprehensive genomic data to add a unique level of personalization or precision to diagnosis and individual patient care planning, including treatment options. Precision or personalized medicine includes the ability to classify individuals into subpopulations that are uniquely or disproportionately susceptible to a particular disease or responsive to a specific treatment. Therapeutic interventions then can be concentrated on those who will benefit, possibly sparing expense and some side effects for those who will not.

Recent research identified a variety of views that cancer patients have about the promises and perils of clinical genomic testing. A 2011 study explored the perceptions of emerging genetic technologies of 69 cancer patients with colorectal, breast, or lung cancers. Importantly, the researchers found that personalized medicine was not a phrase that held particular meaning for many patients, that some patients confused testing for somatic mutations (ie, limited to any mutated cells in the body, excluding germ cells) with germline mutations (ie, mutations in the germ cells that can be passed on to future generations) in discussing their downsides, and that many patients reported a reluctance to undergo whole genome sequencing. The majority of interviewees expressed a willingness to undergo genomic testing, but described concerns and barriers that could hinder test uptake (Figure 2).

“...My mother, her two sisters, and my grandmother have been diagnosed with breast cancer. With such a strong family history, I have always done things to make sure that I was covered in this area. I did self-exams all the time and started mammograms at 36 years old. When the 3D mammograms came out, I paid for them even though it wasn’t covered by insurance.”

— Mia, breast cancer survivor

Figure 2. Patient willingness to undergo genetic testing

<table>
<thead>
<tr>
<th>Type of test</th>
<th>Concerns over incidental information</th>
<th>Concern over information overload</th>
<th>No testing unless there is a clear benefit</th>
</tr>
</thead>
<tbody>
<tr>
<td>Somatic testing</td>
<td>96%</td>
<td>93%</td>
<td>62%</td>
</tr>
<tr>
<td>Predictive</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prognostic</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Germline testing</td>
<td>91%</td>
<td>87%</td>
<td>81%</td>
</tr>
<tr>
<td>Pharmacogenomic</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer susceptibility</td>
<td>87%</td>
<td>81%</td>
<td>81%</td>
</tr>
<tr>
<td>Incidental</td>
<td>96%</td>
<td>93%</td>
<td>91%</td>
</tr>
<tr>
<td>Full sequencing</td>
<td>91%</td>
<td>87%</td>
<td>81%</td>
</tr>
</tbody>
</table>

Themes related to reluctance to test
A 2012 study of 100 patients with breast cancer showed that most participants were willing to undergo molecular testing to assist in the selection of approved drugs (81%) and experimental therapy (59%), if testing was covered by insurance. In addition, 75% of participants were willing to undergo a biopsy to guide therapy, and 46% were willing to undergo research biopsies. Most patients stated they would like to be informed about their research results if these results had implications for therapy (91%), new cancer risk (90%), and other preventable/treatable diseases (87%).

Initial diagnosis from the patient’s perspective

No two people diagnosed with cancer are alike, and each patient has his/her own way of coping with a cancer diagnosis. A patient’s initial reaction might span a range of emotions, including fear, uncertainty, or anger about the diagnosis and unwanted changes cancer will bring to everyday life. In addition, patients may feel numb or confused, or may have trouble listening to, understanding, or remembering what people say at this time because they have shut down mentally, which is especially true when the doctor first informs the patient of a diagnosis of cancer.

Cancer also may change a person’s sense of self and thoughts about the future. Grief is a normal response as patients give up old ideas and begin to develop ways to cope with the new, unwanted changes in their life.

Often, a cancer diagnosis causes patients to think about their own mortality, while simultaneously forcing them to cope with the many new demands that cancer brings. For some, it is easier to face the reality of cancer by learning as much as possible about the disease. This helps with facing the fear of the unknown and uncertainty over what may happen during treatment. Knowledge may serve to lessen their fear.

Breaking bad news

Patient-centered communication skills are needed for physicians to be effective in delivering bad news, such as a diagnosis of cancer. Physicians must be competent in gathering information that allows them to understand...
the unique characteristics of their patients and to manage patients' reactions and address their expectations. Figure 3 offers a patient-centered approach to delivering bad news.\textsuperscript{38}

Despite years of training, physicians often are not prepared to engage patients on such sensitive subjects as a cancer diagnosis and overall treatment costs. Some health care professionals believe better efforts at such training are necessary and note that a few medical schools are addressing this deficiency with medical residents.\textsuperscript{39}

Psychosocial support

The challenges associated with psychosocial obstacles may diminish patients' overall health and functioning. The current medical system deploys its resources largely to address the challenges related to patients' physical health and often ignores the psychosocial challenges. As a result, patients' psychosocial needs often remain unacknowledged and unaddressed in cancer care.\textsuperscript{40}

Among cancer patients, distress may be a minor problem or it could be more serious. Distress screening using tools, such as the NCCN Distress Thermometer and Problem List, can identify patients at risk for physical, psychological, or social conditions that may interfere with access to needed care or adherence to therapy, or contribute to excessive and unnecessary use of scarce medical resources.\textsuperscript{41,42}

Often, a cancer diagnosis causes patients to think about their own mortality, while simultaneously forcing them to cope with the many new demands that cancer brings.\textsuperscript{37}
More options make treatment decisions more complex

After receiving a cancer diagnosis, patients must quickly begin making treatment decisions. With more options and higher expectations of success from today’s new therapy regimens, patients’ choices are becoming increasingly complex. For patients, however, receiving realistic information about the different options of care and the likelihood of successful treatment or adverse effects is difficult.

A survey of 5,044 lung or colorectal cancer patients administered approximately 4 months after diagnosis questioned them about five main issues patients worry about when making decisions about cancer treatment (Figure 4). Overall, 84.7% of participants had at least one worry. The pattern of worry was found to vary along sociodemographic, clinical, and psychosocial factors, including race and ethnicity, illustrating the need to understand the source of patients’ worry and identifying interventions to alleviate their worry.

Patients’ priorities and preferences

Many available studies show that patients with cancer make treatment choices that differ from the choices of the population overall, or even those of health care professionals. This follows from the reality that the perspective of the patient is different from that of a well person. Many cancer patients are willing to undergo major adverse and/or toxic effects for a small objective benefit. These factors help explain the willingness to undertake chemotherapy near the end of life.

Cancer patients have more treatment choices than ever before. According to a recent survey of more than 600 cancer patients, topping the list of priorities as they set out on a care path are a few critical objectives: clinical excellence, convenience and coordination of care, and cost.

Clinical excellence

Almost one-half of respondents (43%) noted that “a physician who specializes in my particular cancer” is the most important factor guiding their decision about where to seek treatment. Many cancer patients reported that they defer to their referring physicians at the time they choose a provider or treatment. However, a new type of consumer of cancer care is emerging—one who is more active in researching providers, more likely to challenge his or her doctor’s recommendations, and more interested in having an active role in the decision-making process.

Convenience and coordination

The four services that surveyed patients indicated they care most about are all related to convenience and coordination of care. In fact, 37% of the surveyed patients indicated that the most valuable feature overall is that “all of my care takes...
place in one building.” Given the strain of managing the physical and emotional toll of their cancer, it seems patients do not want to deal with the added challenge of traveling between widespread facilities or coordinating various details of their care.45

Cost of care
Cost is another area in which patients are taking a more active role in treatment decisions. Even as the general population’s concerns about the high cost of health care increase, many hospital administrators express doubt about whether patients worry about the costs of treatment when they’re battling a life-threatening disease, such as cancer. Yet, the study found that patients do consider costs as a decisive factor when making treatment decisions. Nearly 30% of survey respondents ranked “financial counseling” as one of the five services they value most in a cancer program.45

Patients and second opinions
Many patients today seek a second medical opinion when their diagnosis is uncertain or when treatment options are complicated, unpleasant, or involve risks.46 People with cancer need to feel at ease with their physicians and treatment decisions, which in some instances may prompt patients to seek a second opinion or change doctors entirely.47

The value of second opinions
According to the medical literature, patient-initiated second opinions may offer alternative diagnoses and/or treatment recommendations. Most patients perceive a second opinion to have value, either because it reassures them that the original diagnosis or treatment plan is correct or because it identifies an alternative approach.46

30% of survey respondents ranked “financial counseling” as 1 of the 5 services they value most in a cancer program.45

FACTORS THAT MOTIVATE PATIENTS TO SEEK A SECOND OPINION46

- Confirmation of a diagnosis or treatment
- Dissatisfaction with their first consultation
- A desire for more information
- Hope for a change in the initial diagnosis
- Initial treatment complications or adverse effects

However, some patients are reluctant to seek a second opinion, in part because of their fear of offending their initial physician and/or because they may be overstrained with decision making when confronted with more than one opinion.47 However, oncologists often view the issue more realistically, even considering second opinions as important and necessary. Some oncologists even go as far as encouraging their patients to seek a second opinion, which may contribute to these patients feeling more at ease with the initial cancer diagnosis.47

One factor that may discourage patients from seeking a second opinion is whether their health plan covers the expense.48 However, many insurance plans now acknowledge the importance of a second opinion and are providing coverage for this review process. In the case where an expensive treatment has been recommended in the first diagnosis, some health plans will insist on a second opinion. Though specific situations in which a second opinion is most useful have not been defined, there are certain instances where a second opinion may prove to benefit patients (see box on page 12).48
Cancer coupled with comorbid conditions

Cancer is often experienced in the setting of comorbid conditions, particularly among cancer patients aged 66 years or older (see box). Comorbidity potentially affects the development, stage at diagnosis, treatment, and outcomes of people with cancer. Coexisting illness may compromise the ability of the patient to endure the stress of cancer and its treatment. Most cancer treatment guidelines do not consider the complex interrelations between cancer and comorbidity, and instead manage cancer from a single-disease perspective.

According to the Annual Report to the Nation on the Status of Cancer, 1975-2010, the prevalence of comorbidities was similar among cancer-free Medicare beneficiaries (31.8%), breast cancer patients (32.2%), and prostate cancer patients (30.5%), highest among lung cancer patients (52.8%), and intermediate among colorectal cancer patients (40.7%).

Patients and families, with support from their clinicians, often must take the initiative to ensure that relevant information is shared across the multiple professional health care providers typically involved in providing accurate diagnosis and staging, surgical treatment, adjuvant or definitive chemotherapy and/or radiotherapy, and ongoing management of comorbid problems. However, the complexities of oncology care can make it difficult, if not impossible, for patients and caregivers to carry out this role.

Role of primary care physicians in managing comorbid conditions

Though the size of the overall oncology workforce has remained stable, the specialty continues to age, even as the number of elderly Americans with cancer is growing. Increasing the role of primary care physicians (PCPs) in cancer care has been proposed as one means of addressing this shortfall, despite projections of a looming PCP shortage.

A national survey of physicians caring for cancer patients examined the participation of physicians—1,694 PCPs and 1,621 oncologists—in various aspects of the care of patients with cancer. Two general medical care roles were more often assumed by PCPs than by cancer specialists: managing comorbid conditions and evaluating/treating depression (Figure 5). The involvement of PCPs and cancer specialists in cancer care appears to be complementary.

<table>
<thead>
<tr>
<th>SPECIFIC SITUATIONS IN WHICH A SECOND OPINION IS MOST USEFUL</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>A poorly understood or communicated diagnosis</td>
<td></td>
</tr>
<tr>
<td>An initial diagnosis by a noncancer specialist</td>
<td></td>
</tr>
<tr>
<td>A diagnosis by a cancer subspecialist</td>
<td></td>
</tr>
<tr>
<td>An apparent lack of treatment options</td>
<td></td>
</tr>
<tr>
<td>A treatment plan that involves a clinical trial</td>
<td></td>
</tr>
<tr>
<td>Rare cancers</td>
<td></td>
</tr>
<tr>
<td>A treatment plan that involves surgery as the primary treatment</td>
<td></td>
</tr>
<tr>
<td>A diagnosis that has been made at a small or rural hospital</td>
<td></td>
</tr>
<tr>
<td>A treatment plan that involves aggressive treatment</td>
<td></td>
</tr>
<tr>
<td>A treatment plan that involves specialized treatment</td>
<td></td>
</tr>
</tbody>
</table>

| COMMON COMORBIDITIES AMONG CANCER PATIENTS | |
|---|---|---|
| 16.0% diabetes | 15.5% chronic obstructive pulmonary disease | 9.7% congestive heart failure |

Prevalence of the most common comorbidities in cancer patients aged 66 years or older
When 42 cancer survivors were asked about their perspectives on the role of PCPs in follow-up cancer care, more than one-half expressed strong preferences to receive such care from their cancer specialists (52%). Interviewers elicited barriers and opportunities related to PCP involvement in follow-up care from the perspective of the cancer survivors (Figure 6).54

Preparing for treatment
Because of the often toxic and disabling effects of cancer treatment, cancer prehabilitation can be an effective way to prepare patients for treatment.55 Prehabilitation is defined as one or more interventions performed in a newly diagnosed cancer patient that are designed to improve physical and mental health outcomes as the patient undergoes treatment and beyond. Cancer prehabilitation uses a multidisciplinary approach combining exercise, nutritional, and psychological strategies to prepare patients for the challenges of cancer treatment, such as surgery, chemotherapy, immunotherapy, and radiation therapy.55

See the interview with Ms. Lori McKitrick on pages 14-15, which discusses prehabilitation in more detail.

Integrating palliative care into oncology
A paradigm shift has occurred to approaches that integrate disease-directed therapy and palliative care, such that palliative care is given throughout the continuum of cancer care with the informed preferences of patients incorporated into individualized treatment plans.56-57
PREHABILITATION: HELPING PATIENTS PREPARE FOR CANCER TREATMENT

Lori McKitrick is Senior Director of Clinical Operations at Oncology Rehab Partners in Marlborough, Massachusetts, and works with more than 200 health care systems nationwide in their efforts to implement rehabilitation and prehabilitation services that lead to improved outcomes for patients. Previously, she was Director of Rehab Services at Bon Secours St. Francis in Greenville, South Carolina.

Prehabilitation has been an integral part of treatment in some areas of medicine for many years (e.g., orthopedics), but is just beginning to take hold in oncology. Prehabilitation takes place in the time period between cancer diagnosis and the beginning of treatment. It can include physical and psychological assessments that establish a baseline functional level, identify impairments, and provide targeted interventions designed to improve a patient’s health and potentially reduce the incidence and severity of current and future impairments. Prehabilitation is applicable to all cancer types but is most often employed with head and neck, breast, lung, and prostate cancers.

Ms. McKitrick stated that when patients get stronger through prehabilitation, they may have more treatment options available than if they had not improved the quality of their health and functional ability prior to certain surgical procedures.

The concept still is not entirely accepted or practiced with all cancer patients, though this is changing, according to Ms. McKitrick. Cancer care is beginning to incorporate a practice of “preparing patients for the impending storms they are about to encounter, which could include radiation, chemotherapy, and/or surgery, to counteract the accompanying side effects and physical impairments,” she said. The result is that certain cancer diagnoses will prompt a recommendation for patients to begin a prehabilitation program.

A multimodal approach

Ideally, prehabilitation is practiced using a multimodal approach. Physical impairments could be one side effect of cancer treatment, but there are other concerns—nutrition, distress, and finances—that require a multimodal tactical plan to best prepare patients for their survivorship journey. The goals of prehabilitation include:

- Reduce or remove physical impairments
- Address nutritional deficits
- Address psychosocial needs, which may be related to treatment, family, and/or financial status

“Many health care institutions are creating screening tools, such as physical impairment and nutritional screening tools, so they can identify at-risk patients and refer them to the appropriate professionals.”

“Prehabilitation improves the chance for patients to have procedures that they may not have been able to tolerate in the past because they weren’t strong enough. Among the reasons patients drop treatment protocols is they just can’t tolerate them. They choose quality of life over continuing the treatment.”

![Diagram](https://via.placeholder.com/150)

Source: Adapted from Oncology Rehab Partners’ STAR Program prehabilitation model.
One barrier to prehabilitation is that it could delay patients’ cancer treatment. Ms. McKitrick said it should not delay treatment unless it potentially could lead to a better outcome. The decision to delay treatment is determined by the health care professional who is driving the care. Some patients are seen first by a surgeon who recommends prehabilitation care because he or she has insight into how the surgery may compromise the patient physically during recovery.

A notable example of where prehabilitation can improve patient preparation for care is in radiation treatment for certain breast cancers. For radiation to be most effective, a woman has to be able to position her arm properly within the machine. Prehabilitation can help by increasing her range of motion prior to treatment, thus making it possible for the treatment to have a higher success rate.

Feedback from patients about their prehabilitation experience has been positive, with many noting that the process “allowed them to focus on their wellness,” Ms. McKitrick said.

Tracking outcomes to measure prehabilitation effectiveness

Oncology Rehab Partners has directed a national pilot study that aggregated patient outcomes data to determine whether prehabilitation helped patients shorten their hospital stay, avoid readmissions, return to work more quickly, and/or return to regular functional activities. The initial data look promising, Ms. McKitrick said. For example, lung cancer patients who participated in a prehabilitation program were able to reduce their hospital stays by an average of 2 days.

Many tools are used to assess baseline status for patients entering prehabilitation and to measure the impact of prehabilitation on treatment outcomes. For example, visual analog scales measure distress, pain, and fatigue, and the Functional Assessment of Chronic Illness Therapy measures quality of life and fatigue.

Meeting challenges to implementing prehabilitation

There are a few challenges to implementing prehabilitation. One obstacle is making prehabilitation process-driven and operationalizing it within a health care system that has many competing priorities. This requires creating processes that work, whether it is screening and referral procedures or dedicated prehabilitation-type sessions with patients. The key is to create tools and processes within the hospital, cancer center, physician offices, and rehabilitation departments to develop and implement a multidisciplinary oncology rehabilitation service line within the facility.

In instances in which a treatment center has questioned whether the treatment timeline permits the use of prehabilitation, Ms. McKitrick recommended that the institution review the time that elapses between diagnosis and the patient’s first procedure. As a result, many institutions “are amazed” at the length of the window of opportunity available for the prehabilitation process, Ms. McKitrick said.

Another challenge is teaching and streamlining the prehabilitation concept, with the goal of getting the protocol into physicians’ electronic medical records.

Reimbursement is another challenge. Rehabilitation is covered by third-party payers and by insurance as long as it is medically necessary and patients are demonstrating progress toward their goals. “When rehabilitation is administered in the prehabilitation timeframe, it is typically reimbursed as long as it is labeled as rehabilitation,” Ms. McKitrick said.

The Centers for Medicare and Medicaid Services is gathering data and reviewing prehabilitation reimbursement policies under both the Medicare Access and Children’s Health Insurance Program (CHIP) Reauthorization Act, which should be finalized in 2017, and the Oncology Care Model for payment and health care delivery.
Health care professionals who recognized the need to focus on quality of life at the same time as disease treatment pioneered the conceptual shift at the core of palliative care away from the choice of either pursuing disease-directed curative therapies or else choosing hospice.

The Center to Advance Palliative Care polled 950 voters as part of public opinion research undertaken to determine the best language to use to describe palliative care in such a way as to make it something people would want for themselves or their loved ones (see box above).

Palliative care clinicians assess and treat physical, emotional, and spiritual or existential distress. Palliative care consists of a team approach that involves physicians, nurse specialists, and health care professionals with expertise in psychological support, spiritual care, and physical therapies. Currently, specialty palliative care is most commonly based in hospitals and is offered as a consultative service; however, increasingly it is being seen in outpatient settings, at home, and in long-term care facilities. Advanced practice providers who function in the acute care setting are valuable members of the oncology health care team and instrumental in coordinating palliative care services across settings.

The Institute of Medicine recommends that all people with advanced illness have access to palliative care specialists. However, there are not enough of these highly trained providers to meet the current or future need in the United States, especially as people live longer and the population ages. One way to meet this need is to integrate palliative care into primary care, where appropriate, and reserve scarce palliative care services for the most complex cases.

**WHAT IS PALLIATIVE CARE?**

Palliative care is specialized medical care for people with serious illnesses. This type of care is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis.

- The goal is to improve quality of life for both the patient and the family.
- Palliative care is provided by a team of doctors, nurses, and other specialists who work with a patient’s other doctors to provide an extra layer of support.
- Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.

Health care professionals who recognized the need to focus on quality of life at the same time as disease treatment pioneered the conceptual shift at the core of palliative care away from the choice of either pursuing disease-directed curative therapies or else choosing hospice. The Center to Advance Palliative Care polled 950 voters as part of public opinion research undertaken to determine the best language to use to describe palliative care in such a way as to make it something people would want for themselves or their loved ones (see box above).

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**GOALS OF PALLIATIVE CARE**

- Treat symptoms, including pain, nausea, breathlessness, insomnia, and other physical issues caused by cancer or its treatment
- Manage emotional and social needs, including anxiety, depression, and relationship issues
- Address spiritual needs or concerns
- Address practical needs, such as transportation and financial concerns
- Provide support for family, friends, and caregivers

*Perspectives on Palliative Care and Advance Care Planning, an Issues in Focus report sponsored by Genentech, takes a closer look at the benefits, challenges, and opportunities for patient-centered communication and shared decision making as they relate to palliative care, advance care planning, and timely hospice referrals.*
Much of the appeal of palliative care flows from its emphasis on providing support that enables patients to remain for as long as possible at home or in the least restrictive and least intensive setting of care and that ensures that patients receive care consistent with their values, goals, and informed preferences. These include avoiding the discomfort of unwanted tests and procedures that may not be necessary or beneficial. The best palliative care occurs when patients and their families work together with the health care team.

**Summary**

*The Patient Voice Across the Cancer Care Continuum: Screening, Diagnosis, and Prehabilitation* emphasizes the importance of the patient perspective when making decisions about:

- The possible benefits and harms associated with cancer screening and challenges to adequate cancer screening
- The use of genomics, which may provide personalization to diagnosis and individual patient care planning
- The patient-centered approach and psychosocial support clinicians should provide when discussing a cancer diagnosis
- The complexity of treatment options and its effect on patient decision making
- Preparations for cancer treatment, including prehabilitation and the integration of palliative care into disease-directed therapy

Insights into the patient voice through other phases of cancer care are further explored in two companion reports in this series: *The Patient Voice Across the Cancer Care Continuum: Treatment and The Patient Voice Across the Cancer Care Continuum: Survivorship, End of Life, and Other Cancer Care Issues.*

**Appendix/Resources**

**Genentech Resources**

Below is a sampling of initiatives and resources sponsored or supported by Genentech to assist patients, family caregivers, clinicians and other stakeholders throughout the cancer care continuum.


Each interactive session in the Care Management Workshop Series provides an opportunity for care managers to learn and discuss key patient issues and challenges. Experts lead the 1- to 2-hour workshops, which can be attended live or via webcast. In oncology, the following workshop topics are available: Foundations of Oncology, Palliative Care, Psychosocial Issues in Cancer Care, and Cancer Survivorship. The objectives of the care management workshops are to equip care managers with the skills to better guide and advocate for patients during their treatment journey and to improve the efficiency and quality of care for patients living with chronic and advanced illness.

**Journey Forward** ([http://www.journeyforward.org/](http://www.journeyforward.org/))

Journey Forward was developed in response to the 2005 Institute of Medicine report *From Cancer Patient to Cancer Survivor: Lost in Transition*, which revealed poor cancer care coordination and a deep lack of awareness about survivorship care needs among cancer survivors. A unique collaboration involving Genentech began in 2008 to develop tools for oncology professionals and primary care physicians, as well as cancer survivors, to address needs for coordinated follow-up care once active treatment comes to an end. These include free survivorship care plan builder software for clinicians, a medical history builder resource for survivors, a directory of survivorship resources and a searchable online library of survivorship articles available from the Web site. Included in the patient tools are two mobile phone applications (apps)—the Self-Care app and the My Care Plan app.

**Love Your Colon** ([http://loveyourcolon.org/](http://loveyourcolon.org/))

Love Your Colon, founded in 2007, is an initiative designed to increase awareness of colorectal cancer and the importance of screening. The goal is to increase screening rates and decrease the number of colorectal cancer-related deaths. Through customizable resources on the Web site, communities at-large, health care providers, employers, and payers can educate and encourage their citizens, patients, employees, and members to take action against colorectal cancer.
General Resources
Below is a sampling of initiatives and resources sponsored by public and private organizations to support patients, family caregivers, clinicians and other stakeholders throughout the cancer care continuum. Genentech does not endorse these organizations nor the views they express or the products/services they offer. These listed organizations below are provided solely for information purposes. Genentech does not control or guarantee the accuracy, relevance, timeliness or completeness of information provided by these organizations.

Cancer and Careers
(http://www.cancercareandcareers.org/en)
Cancer and Careers helps nearly 300,000 people each year — online, in print, and in person — by providing valuable information and resources via expert advice, interactive tools, and educational events.

CancerCare®
(http://www.cancercare.org/)
Founded in 1944, CancerCare is the leading national organization providing free, professional support services and information to help people manage the emotional, practical, and financial challenges of cancer.

Cancer Experience Registry
(https://www.cancerexperienceregistry.org/)
The Cancer Experience Registry is a grassroots effort to engage participants who have been impacted by cancer to answer questions about their social and emotional experiences and needs throughout their cancer journey. It is a research project driven by people living with cancer and their caregivers.

Cancer Financial Assistance Coalition (CFAC)
(www.cancerfac.org)
CFAC is a coalition of financial assistance organizations joining forces to help cancer patients experience better health and wellbeing by limiting financial challenges.

Cancer.Net
(http://www.cancernet.net/)
Cancer.Net provides timely, comprehensive, oncologist-approved information from the American Society of Clinical Oncology (ASCO), with support from the Conquer Cancer Foundation. Cancer.Net brings the expertise and resources of ASCO to people living with cancer and those who care for and about them to help patients and families make informed health care decisions.

Cancer Support Community (CSC)
(http://www.cancersupportcommunity.org/)
As the largest professionally led, nonprofit network of cancer support worldwide, the CSC is dedicated to ensuring that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community. CSC achieves its mission through three areas: direct service delivery, research, and advocacy. The organization includes an international network of affiliates that offer the highest quality social and emotional support for people impacted by cancer, as well as a community of support available online and over the phone. The Research and Training Institute conducts cutting-edge psychosocial, behavioral, and survivorship research. CSC furthers its focus on patient advocacy through its Cancer Policy Institute, informing public policy in Washington, DC, and across the nation.

Coping® With Cancer
(http://www.copingmag.com/cwc/index.php/about/about_coping/about_us/)
The Coping with Cancer Web site is a complete online experience that educates and inspires. It is presented in a warm and friendly, easy-to-use format, and provides information by specific cancer type, general knowledge about living with cancer, and wellness and inspirational topics.

Global Resource for Advancing Cancer Education (GRACE)
(cancergrace.org)
GRACE provides expert-mediated information on current and emerging cancer management options in order to empower patients, caregivers, and health care professionals to become direct partners in cancer care.

Critical Mass: The Young Adult Cancer Alliance
(criticalmass.org)
Critical Mass is a community-powered advocacy organization whose mission is to transform the care and treatment of young adults with cancer.

Informed Medical Decisions Foundation
(http://www.informedmedicaldecisions.org/)
The Informed Medical Decisions Foundation, now a division of Healthwise, has been working to advance evidence-based, shared decision making since 1989. They believe the only way to ensure that high-quality health care decisions are being made is for fully informed patients to participate in a shared decision-making process with their clinician. Through research and advocacy efforts, the foundation is dedicated to helping people make better health decisions.

MetaCancer Foundation
(metacancer.org)
The MetaCancer Foundation provides resources and support for metastatic cancer survivors and their caregivers. MetaCancer encourages dialogue among those with very different types of metastatic cancer (breast, prostate, colorectal, ovarian, bladder/urinary, skin, lung, testicular, among others), even though respective treatment protocols and medical issues may seem to have little in common with each other. The common bonds are the psychological and emotional realities faced by anyone living with metastatic cancer. MetaCancer provides resources for everyday living, opportunities for creative reflection, and possibilities for you to “go meta”: to live beyond your diagnosis right now with strength, grace, and peace.
Mobile Resources Selected by the Memorial Sloan Kettering Library: Patients & Caregivers
(http://libguides.mskcc.org/c.php?g=245150&p=1632654)
Mobile resources are categorized as follows: Health-U.S. Government, About Cancer, Quit Smoking, Medication-Related Resources, Diet and Fitness, Signs and Symptoms, Emergencies and First Aid, Resources to Feed the Mind, Local Amenities and Other Useful Health sites and apps.

My Cancer Circle
(http://mycancercircle.lotsahelpinghands.com/)
My Cancer Circle, powered by Lotsa Helping Hands, is a simple online tool that helps organize the community of people who want to help caregivers of patients with cancer. It coordinates their efforts to more efficiently support the caregiver and the loved one facing cancer. My Cancer Circle coordinates volunteer activities, including meals, transportation to medical appointments and other tasks; provides a private space where community members can offer words of support and encouragement and where caregivers can post updates and information about their loved one; and schedules offers to give caregivers a break or to do something special for them.

National Cancer Institute (NCI)
(http://www.cancer.gov)
NCI offers free, credible, current, comprehensive information about cancer prevention and screening, diagnosis and treatment, research across the cancer spectrum, clinical trials, and news and links to other NCI Web sites. The Web site contains excellent resources for both patients and caregivers.

National Cancer Legal Services Network (NCLSN)
(www.NCLSN.org)
NCLSN promotes access to health care and seeks to increase the availability of legal services for people living with cancer, their families, and caregivers. Through direct work, educational efforts and advocacy, this multidisciplinary coalition helps to alleviate the legal and economic consequences of cancer so that those affected may focus on their medical care and quality of life. The NCLSN supports the efforts of individuals and organizations focused on meeting the legal needs of the cancer-affected community. It augments the voice of disparate services, creates a forum for and nascent legal advocacy groups, and facilitates the development of similar programs.

National Coalition for Cancer Survivorship (NCCS)
(http://www.canceradvocacy.org/)
NCCS’ mission is to advocate for quality cancer care for all people touched by cancer. Founded by and for cancer survivors, NCCS created the widely accepted definition of survivorship and defines someone as a cancer survivor from the time of diagnosis and for the balance of life.

National Colorectal Cancer Roundtable (NCCRT)
(http://nccrt.org/)
NCCRT, established by the American Cancer Society and the Centers for Disease Control and Prevention in 1997, is a national coalition of public, private, and voluntary organizations and invited individuals dedicated to reducing the incidence of and mortality from colorectal cancer in the United States, through coordinated leadership, strategic planning, and advocacy. The NCCRT campaign “80% by 2018” aims to reach 80% screening rates for colorectal cancer by 2018, and has over 1,000 organizations pledging support across the United States.

NCCN Patient and Caregiver Resources
(nccn.org/patients)
NCCN Guidelines for Patients® are translations of the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) and are designed to help patients with cancer talk with their physicians about the best treatment options for their disease. This Web site provides state-of-the-art cancer treatment information in easy-to-understand language.

PatientsLikeMe®
(https://www.patientslikeme.com/)
Members of PatientsLikeMe contribute directly to research through data sharing to advance understanding of the disease in a way that can accelerate discovery and improve care. Patients have the opportunity to share both personal stories and health data about their conditions to help put their disease experiences in context and find answers to the questions they have. In addition, PatientsLikeMe’s Open Research Exchange (https://www.openresearchexchange.com/) has created an open platform for developing, validating, and sharing health-outcome measures that better reflect patients’ experiences with a disease, and assess health and quality of life in ways that matter to patients.

Preparatory Education About Clinical Trials (PRE-ACT)
(http://www.cancer.net/navigating-cancer-care/how-cancer-treated/clinical-trials/pre-act)
This educational program is designed to provide general information about clinical trials. PRE-ACT was developed with support from the National Cancer Institute to help cancer patients better understand what clinical trials are and how they work.

Reimagine
(https://reimagine.me/)
Reimagine is a powerful collection of tools that are designed to help everyone in the cancer community feel better, all based on The Seven Pillars of Personal Strength™. The program consists of 10 self-paced online modules with more than 100 activities, videos, and live sessions. The Core Program will help patients, survivors, friends, and family learn a proven set of skills for navigating the challenges of cancer and life. It is an essential component of any Survivorship Care Plan and a powerful tool for people who score a four or above on the Distress Thermometer.
**Triage Cancer**
(http://triagecancer.org/)

Triage Cancer works to address cancer-related health disparities through the delivery of cancer survivorship education, particularly information related to accessing care. Information is tailored to specific cancer-community audiences, including childhood cancer survivors and their parents, adolescents and young adults, seniors, newly diagnosed patients, individuals who have completed treatment, individuals with advanced disease, caregivers, advocates, and health care professionals.

**US Preventive Services Task Force (USPSTF)**
(http://www.uspreventiveservicestaskforce.org)

USPSTF develops recommendations for preventive services, such as screening tests, counseling services, and preventive medications, based on a review of high-quality scientific evidence.

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**References:**


Issues in Focus: The Patient Voice Across the Cancer Care Continuum

A series of informational white papers provided by Genentech, South San Francisco, CA

Produced by Emron, Wayne, NJ
www.emron.com
Issues in Focus
The Patient Voice Across the Cancer Care Continuum
Treatment
Disclosure

The content of this report was prepared by Emron on Genentech’s request with the guidance of an editorial board and is based on published literature. Statements and opinions contained in the report do not necessarily reflect those of Genentech or the editorial board.
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Suggested Citation
The Patient Voice Across the Cancer Care Continuum: Treatment.
South San Francisco, CA: Genentech; 2016.

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In Memoriam
This edition is dedicated to the memory of Jan Gbur who served as project manager for this report. Her voice was silenced by a short battle with cancer. She is missed and fondly remembered.
Leaders representing a diverse group of stakeholders from across the United States came together at Genentech’s corporate campus in South San Francisco, California, to attend the 2016 Genentech Oncology Institute on May 4–5, 2016. This year’s program focused on the cancer patient journey through prevention, diagnosis, treatment decisions, and outcomes. Cancer survivors shared their experiences through video vignettes during the event. Commentary from these vignettes regarding the following survivors are included in this report.

Cancer survivor profiles

Mia is a 47-year-old breast cancer survivor
She describes herself as being healthy and active and following a vegan diet. She started dancing at the age of 5 and has been a fitness instructor for over 30 years. With a strong family history of breast cancer, Mia shares her thoughts about proactive breast cancer screening and patient decision making.

Glenn is a 63-year-old chronic lymphocytic leukemia (CLL) survivor
He describes himself as a significantly overweight couch potato until the age of 47 when he took up and became addicted to running. He was diagnosed with CLL as a result of a routine physical exam. After receiving his diagnosis on the telephone, Glenn shares his experience with gathering timely information from Web sites and chat rooms.

Jose is a 55-year-old lung cancer survivor
He speaks about his emotional struggles, concerns about his job and ability to work, and what he has learned from other cancer survivors.

Jennifer is a 31-year-old ovarian cancer survivor
She was diagnosed with ovarian cancer at age 17 during a pregnancy. She speaks about her trust in her doctors, fears of seeming weak, and the need to be strong for her family.

CANCER PATIENTS BY THE NUMBERS

<table>
<thead>
<tr>
<th>Category</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Estimated number of new cases of cancer in 2016</td>
<td>1,685,210</td>
</tr>
<tr>
<td>Estimated number of children and adolescents (ages 0–19 years) diagnosed with cancer in 2014</td>
<td>15,780</td>
</tr>
<tr>
<td>Estimated number of deaths from cancer in children and adolescents (ages 0–19 years) in 2014</td>
<td>1,960</td>
</tr>
<tr>
<td>Number of cancer survivors in 2014</td>
<td>Nearly 14.5 million</td>
</tr>
</tbody>
</table>

Introduction

Many Americans know all too well the devastation cancer can bring. Cancer spans all ages—from children to adolescents/young adults, working-age adults, retired adults, and the frail elderly—and affects people across the socioeconomic spectrum and from all ethnicities and cultures. The American Cancer Society estimates that nearly 1.7 million new cancer cases will be diagnosed in the United States in 2016, and that more than 595,000 Americans will die from some form of the disease.

The patient experience with cancer is at the forefront of the public eye, especially with a new, national “Moonshot” initiative to eliminate cancer instituted in 2016. This $1 billion initiative will focus on making the most of federal investments, targeted incentives, private-sector efforts from industry and philanthropy, patient-engagement initiatives, and other mechanisms to accelerate the development of new cancer detection methods and treatments.
Due to the nature of the disease, cancer’s influence is far reaching and often calls upon the support of family members as unpaid caregivers. The experience of cancer can also strain or negatively impact patients’ socioeconomic status due to the financial burden of cancer treatments, loss of work, and long-term consequences of cancer. In addition, the physical and psychosocial effects of cancer may linger long after active treatment ends.

A 20% improvement in the 5-year relative survival rate for all cancers from 49% in 1975 to 69% in 2011 means that more people are living with cancer as a chronic disease. Survival is improving due to advanced diagnostics, less toxic and more targeted therapies, the availability of second- or even third-line therapies, and improved surgical and radiation therapy techniques.

Cancer is a complicated disease steeped in complex terminology, and having cancer is not like having any other kind of illness. Cancer is an experience that only those who have had cancer seem to truly understand; yet, people do not have uniform or parallel responses to having cancer. A cancer patient’s needs and experience change dramatically over the course of cancer care, and best practices for addressing these needs vary significantly across the patient journey.

In order to provide quality of care and life, it is important to understand the attitudes, aptitudes, needs, and experiences of cancer patients so that providers can effectively communicate with them, seek their involvement in decision making and goal setting, and support living with cancer.

The Patient Voice Across the Cancer Care Continuum, provided in three parts, is the fourth installment in the Issues in Focus series sponsored by Genentech. Its goal is to take a closer look at cancer through the perspective of the patient—commonly called the “patient voice”—across the continuum of cancer care, which includes screening, diagnosis, treatment, survivorship, end-of-life care, and other cancer care issues.

The second part, The Patient Voice Across the Cancer Care Continuum: Treatment, explores the physical, psychosocial, and financial dynamics patients must contend with as they navigate through the myriad of complex decisions associated with cancer treatment. The first and third parts, The Patient Voice Across the Cancer Care Continuum: Screening, Diagnosis, and Prehabilitation and The Patient Voice Across the Cancer Care Continuum: Survivorship, End of Life, and Other Cancer Care Issues, expand our understanding of the patient voice, as patients navigate other phases of the cancer care continuum.
TREATMENT

Treatment decision making and goal setting

The context of cancer treatment can be particularly challenging for patients and their families. The myriad of complex decisions they are faced with are numerous and can be overwhelming, especially when first diagnosed. For example, there may be a number of interconnected effective therapies for a particular cancer, applied at different points in the treatment process, and with various risks and benefits. This may frequently lead to patient “decision-awareness” problems about what decisions are supposed to be made, as well as how they ought to be made. Also, different specialists direct various treatments (eg, surgeons, radiation oncologists, medical oncologists) and may be located at diverse locations without access to the same electronic health records system. Coordinating care can be a burden for patients, and problems can arise if providers on the team are unaware of treatment status and patient response. Patients newly diagnosed with cancer have a steep learning curve on collaborating with clinicians to make complex decisions about treatment and to participate in the coordination of their care.

Cancer treatment plans—a roadmap for patients and physicians

Cancer care has a number of unique attributes that make treatment planning vital. It can be complex, toxic, intense, expensive, disruptive, life-threatening, and protracted. It can also require lifelong surveillance due to the possibility of cancer recurrence or late complications.

Given the complexity of cancer care, a written cancer treatment plan that is incorporated into the patient’s care at the time of treatment initiation is critical. It is a document that is given to the patient, family, and other treating physicians that serves to keep everyone on the treatment team informed of the path of care and identifies who is responsible for each portion of that care. A written treatment care plan typically includes:

- Specific tissue diagnosis and stage, including relevant biomarkers
- Initial treatment plan and proposed duration
- Expected common and rare toxicities during treatment and their management
- Expected long-term effects of treatment
- Who will take responsibility for specific aspects of treatment and their side effects
- Psychosocial and supportive care plans
- Vocational, disability, or financial concerns and their management
- Advance care directives and preferences

A cancer treatment plan is altered when new information, such as a change in treatment response or in patient preference for treatment, results in a need for a change in treatment. An altered plan gives the patient a chance to bring up new information, such as the need to take a break from chemotherapy.

The American Society of Clinical Oncology (ASCO) has developed online, two-page templates that have two distinct parts—a treatment plan and a summary (TPS). Oncologists can use these tools to improve physician-patient
and physician-physician communication. In a pilot study, newly diagnosed patients with Stages 0 through III breast cancer were surveyed 2 to 4 weeks after receipt of a TPS. The 157 participants were asked about patient satisfaction and communication with physicians as a result of receiving the TPS. Most (72.0%) stated that the TPS increased their peace of mind, and most indicated that they are very likely (56.0%) or somewhat likely (34.4%) to refer back to the document. Figure 1 outlines the patients’ perceptions about the impact of the TPS on communication with physicians.

**Shared decision making in cancer care**

The primary objectives of shared decision making are that patients are fully informed of their treatment options and the trade-offs between risks and benefits, and that their values and preferences are incorporated into treatment decisions.

Shared decision making is important for several reasons. Patients and their families are ultimately subjected to the outcomes of treatment decisions related to their cancer care, so it is the ethical responsibility of clinicians to facilitate patient autonomy. If patients are engaged in their care, then they are likely to be more informed, willing to discuss the risks and benefits of different treatment options, and more satisfied with the clinical encounter. They may even have better psychosocial and, in some cases, physical outcomes.

"I went through a lot of self-healing from the time I got the diagnosis until the time that I went back, reading a lot of things, doing a lot of meditation. I mean, I ordered every juicer there was. The deciding factor for why I decided to go ahead and do my treatment was because I just did it on my own timetable. It wasn’t the decision that the doctor decided for me, which is very, very important to me."

— Mia, breast cancer survivor

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**Figure 1. Patient perceptions about communication with physicians after receiving a treatment plan and summary (N=157)**

<table>
<thead>
<tr>
<th>Perception</th>
<th>Very much</th>
<th>Moderately</th>
<th>A little</th>
<th>Not at all</th>
<th>Not sure/refused</th>
</tr>
</thead>
<tbody>
<tr>
<td>The patient understood the document</td>
<td>73.2%</td>
<td>22.9%</td>
<td>1.9%</td>
<td>0.6%</td>
<td>1.2%</td>
</tr>
<tr>
<td>The document improved communication with physician</td>
<td>57.3%</td>
<td>32.5%</td>
<td>4.4%</td>
<td>1.3%</td>
<td>4.5%</td>
</tr>
<tr>
<td>The document improved communication between physicians</td>
<td>52.9%</td>
<td>25.5%</td>
<td>3.2%</td>
<td>4.4%</td>
<td>14.0%</td>
</tr>
<tr>
<td>The document is or will be useful</td>
<td>68.4%</td>
<td>23.0%</td>
<td>5.3%</td>
<td>2.0%</td>
<td>1.3%</td>
</tr>
</tbody>
</table>

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Oncologists’ support of shared decision making

Survey results suggest that oncologists are interested in enabling shared decision making with their patients; however, it is often a complex undertaking in the cancer setting. There may be high levels of uncertainty, and providers must weigh the risks of different treatments with potential benefits and explain those to patients. Decisions must be made at multiple points over the course of care, and patients may not be aware of how one decision leads to subsequent decisions. Finally, decisions often need to be revisited at various points along the cancer care continuum as patients’ goals and preferences change.

Oncologists encounter a number of barriers to implementing shared decision making:

- Time constraints
- Perceptions that shared decision making cannot be applied because of patient characteristics, such as anxiety, lack of information, and inability to participate
- The nature of the clinical situation
- Overly high workloads among physicians
- Insufficient provider training
- Inadequate clinical information systems

In addition, it is important for oncologists to consider what perceptions patients bring to discussions of prognosis because such conversations are necessary for patients to be fully informed about the likely course of their disease and to contribute to the choice of treatment. These discussions need to be thought of as a process to be revised and updated over time in order for patients to make informed treatment choices. Physicians fear that honest discussions about prognosis will take away hope; however, evidence suggests that hope is maintained even with truthful discussions that inform the patient that there is no chance of cure. Patients not only need explicit prognostic information, but also reassurance that they won’t be abandoned when transitioning to palliative care.

Patients vary in their preferred level of participation in cancer treatment decision making. Patient characteristics, such as age, sex, race/ethnicity, cancer type, individual values and beliefs, and health literacy level, may affect these preferences. The extent of the disparity in health literacy is probably growing with increasing options and the complexity of cancer care, which require more involvement of patients in decision making. The problem is further exacerbated by growing numbers of elderly people who bear a greater burden of cancer and have a greater prevalence of low health literacy. As a result, older patients may be more passive in interacting with their physicians and have more communication barriers. Older patients may bring family members or caregivers to their appointments, which can facilitate the decision-making dynamic or interfere with it, such as when they have treatment preferences that differ from those of the patients.

"We went through all of the different treatment options. My mom and my aunt asked a lot of different questions. I would always look at my mother and ask her what she thought. I was 17 and really did not know what was going on. I think, at the time. We just listened to what the doctors told us; we trusted them wholeheartedly. We did what they said would make me better." — Jennifer, ovarian cancer survivor

13. "We went through all of the different treatment options. My mom and my aunt asked a lot of different questions. I would always look at my mother and ask her what she thought. I was 17 and really did not know what was going on. I think, at the time. We just listened to what the doctors told us; we trusted them wholeheartedly. We did what they said would make me better." — Jennifer, ovarian cancer survivor

16. Physicians fear that honest discussions about prognosis will take away hope; however, evidence suggests that hope is maintained even with truthful discussions that inform the patient that there is no chance of cure. Patients not only need explicit prognostic information, but also reassurance that they won’t be abandoned when transitioning to palliative care.
Identifying patients with low health literacy

Patients with cancer must make decisions at times of physical and emotional distress, and health literacy is critically important for those decisions. Health literacy does not necessarily equate to reading ability or the level of education, but rather comprises a complex combination of reading, listening, analytical, and decision-making skills. It also requires the ability to synthesize these skills and apply them to health care situations. A well-educated patient who thrives in other areas (e.g., the workplace) may not have an adequate literacy to navigate a health care environment. In addition, many patients may be interacting within the health care system for the first time.

Because every patient is unique, health care providers should not assume the information given is understood, even if patients look over the written information and state that they do understand it. There are a number of indicators that a patient may have low health literacy (see box).

A number of general tools are available to assess health literacy (e.g., the Short Test of Functional Health Literacy in Adults and the Rapid Estimate of Adult Literacy in Medicine). However, researchers at Virginia Commonwealth University reported that they have developed a tool—the Cancer Health Literacy Test (CHLT)—that can accurately measure cancer health literacy along a continuum (CHLT-30), as well as quickly identify patients with limited cancer health literacy (CHLT-6). An instrument specific to cancer is useful because of the complex treatment choices patients face along with the increased demand for self-care.

Cancer communication tailored to patients with low health literacy needs to be understandable and logical from the patient’s perspective and experience. Physicians need to be explicit and clearly communicate what patients need to do, when they should do it, and why these actions will be beneficial for them.

Use of decision aids in the shared decision-making process

Decision aids help patients recognize that a decision needs to be made, provide information about the available options and their expected risks and benefits, and are designed to help patients clarify their attitudes toward risks or preferences about possible outcomes. For patients with cancer, using decision aids can increase knowledge about options and expected benefits and harms and may result in an improved association between choices and values.

Over the past 20 years, with the increasing use of technology, Internet-based decision aids have become more common. Also, using decision aids to clarify values has become more prevalent.

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**INDICATORS A PATIENT MAY HAVE LOW HEALTH LITERACY**

- Asks fewer questions
- Identifies medications by appearance rather than by label information
- Unable to name medications, explain their purpose, or give the dosage
- Unable to provide a coherent, sequential medical history
- Lack of adherence to treatment protocol
- Does not follow through with tests or referrals
- Frequently misses appointments
- Incomplete registration forms

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Physicians fear that honest discussions about prognosis will take away hope. However, evidence suggests that hope is maintained even with truthful discussions that inform the patient that there is no chance of cure.
Recently published articles have established that a substantial number of cancer patients use the Internet to gather information about their respective diagnoses.\(^{23}\) Five hundred patients receiving care at a National Cancer Institute (NCI)-designated comprehensive cancer center were surveyed to determine how they use the Internet to gain information about their diagnoses, and 315 (63\%) had searched the Internet for information about cancer. Figure 2 shows the reasons these patients used the Internet and the type of information they were looking for.\(^{23}\)

A review of the literature conducted in 2011 revealed that most studies about Internet use among patients are conducted in primarily Caucasian, insured populations.\(^{24}\) A recent survey was fielded to cancer patients at a public health care facility serving a largely uninsured, minority population and looked at Internet access, medical Internet use, and specific education needs. Minorities, primarily African-American and Hispanic, represented 78.0\% of the 291 patients surveyed. Only 36.8\% (n=107) of the patients had Internet access, with most having access at home. Two-thirds of these reported that they used the Internet to research their cancer diagnosis.\(^{24}\)

There are many Web sites, books, and magazines that provide health information to the public. The American Cancer Society, ASCO, the Food and Drug Administration, the Federal Trade Commission, and others have developed resources about evaluating cancer information and safeguarding patients and families from cancer misconceptions and possible cancer treatment scams.

Assessing treatment options using Internet sources
It is important and challenging for medical providers to understand the prevalence and characteristics of patients using the Internet, reasons for Internet use, and the effectiveness of currently available Web sites in providing useful health-related information to patients.\(^{23}\)

“My doctor told me that I should have a normal life expectancy, and as I was driving home, I was thinking to myself, “Wait a minute, that word ‘should’ means there is a possibility I won’t have a normal life expectancy.” And that’s when the panic started to set in. I went on the Internet and unfortunately the very first hit was an old Web site and all I read was a typical life expectancy of 2 years.”
— Glenn, chronic lymphocytic leukemia survivor\(^{4}\)

Figure 2. Reasons for Internet use and common information sought (n=315)\(^{23}\)

<table>
<thead>
<tr>
<th>Main reasons for searching</th>
<th>Percentage of patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Develop questions to discuss with physician</td>
<td>52.1%</td>
</tr>
<tr>
<td>Verify information received from physician</td>
<td>39.4%</td>
</tr>
<tr>
<td>Find alternative treatments</td>
<td>27.6%</td>
</tr>
<tr>
<td>Still have questions after office visit</td>
<td>23.2%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Common information sought</th>
<th>Percentage of patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment options</td>
<td>61.3%</td>
</tr>
<tr>
<td>Prognosis</td>
<td>58.1%</td>
</tr>
<tr>
<td>Side effects of treatment</td>
<td>49.5%</td>
</tr>
<tr>
<td>Symptom management</td>
<td>40.0%</td>
</tr>
<tr>
<td>Coping with disease</td>
<td>28.9%</td>
</tr>
<tr>
<td>Alternative treatments</td>
<td>27.6%</td>
</tr>
<tr>
<td>Clinical trials</td>
<td>23.5%</td>
</tr>
</tbody>
</table>
NCI has developed guidance to help identify evidence-based information that patients and family members can trust (see box).²⁵

**Patient activation in cancer**

Patient activation is defined as an individual’s knowledge, skill, and confidence in managing their health and health care. Unlike health literacy, activation addresses the motivational elements and mindset to take action.²⁶ Patients with high levels of activation understand their role in the care process, feel capable of fulfilling that role, and are more likely to engage in positive health behaviors and to manage any long-term health conditions more effectively. Patients with low levels of activation are less likely to ask questions, seek help when they need it, follow doctors’ advice, and manage their health when no longer treated. Measuring patient activation helps clinicians personalize the level of support and services that need to be provided to their patients in order to improve outcomes, avoid complications, and experience better satisfaction with their care.²⁶

The Patient Activation Measure (PAM) is a commonly used patient-reported measure that contains 13 statements related to beliefs, knowledge, and confidence for self-management. Patients rate their agreement or disagreement with each statement using a 4-point Likert scale resulting in an activation score of 0 to 100, which is useful for tracking

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"My family lives out of state and I chose not to tell them because I really didn’t have the answers. Everything moved so fast. It was like you’re going to do this now, and do this, and do that, and there was so little information. I was a little bit afraid of venturing onto the Internet and seeing what information I was going to find out."

— Jose, lung cancer survivor

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**QUESTIONS TO DETERMINE THE CREDIBILITY OF ONLINE HEALTH INFORMATION**²⁵

1. **Who manages this information?** The person or group that has published health information online should be identified somewhere.

2. **Who is paying for the project, and what is their purpose?** This information should be in the “About Us” section.

3. **What is the original source of the information that they have posted?** The source of information that was originally published in a research journal or a book should be identified.

4. **How is information reviewed before it gets posted?** Most health information publications should have someone with medical or research credentials review the information before it gets posted.

5. **How current is the information?** Online health information sources should indicate when the information was posted or last reviewed.

6. **If they are asking for personal information, how will they use that information and how will they protect your privacy?** Personal information should not be shared until the policies under which it will be used are understood and the user is comfortable with any risk involved in sharing information online.
In a 2007 national health-tracking household survey, people with cancer tended to have higher activation levels compared with other chronic conditions.\textsuperscript{28} In another study, more activated patients were also significantly more likely than less activated patients to have obtained cancer screening mammography and Pap smear tests.\textsuperscript{29} However, physicians play an important role in patient activation. A randomized survey of chronically ill patients showed that a higher perceived quality of interpersonal exchange with physicians, perceived greater fairness in the treatment process, and more out-of-office contact with physicians were associated with higher levels of patient activation.\textsuperscript{30}

In a 2007 national health-tracking household survey, people with cancer tended to have higher activation levels compared with other chronic conditions.\textsuperscript{28} Four levels of patient activation illustrate how patients differ at each level (Figure 3).\textsuperscript{26}

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**Patients' perspectives on active cancer treatment**

Communication between patients and clinicians during the treatment phase focuses on planning and participating in cancer treatments. This is a time when patients frequently experience uncomfortable side effects, such as fatigue, nausea, and pain. They also may want to discuss changing or stopping treatment, depending on the initial response and side effects.\textsuperscript{31}

One study analyzed interviews from 120 patients and 17 family members of patients with cancer to identify those aspects of clinician-patient communication that were most relevant, meaningful, and pertinent to them. The two functions of communication that these interviewees were most aware of and sensitive to were the need for effective information exchange and a good clinician-patient relationship (see box on page 11).\textsuperscript{32}

There are, however, specific challenges for physicians that hinder the development of a trusting relationship with their patients. Some of these are patient dissatisfaction with the practice of medicine in its current format, a systemic malaise among physicians related to the mandate around electronic health records, hidden medical errors that are linked to failure to perform a physical exam of the patient, and the loss of “ritual” in the doctor-patient visit.\textsuperscript{33}

**Patient-reported outcomes**

A critical step in amplifying the voice of cancer patients and involving them in their care is to capture their experience.\textsuperscript{34} Patient-reported outcomes (PROs) directly involve patients
rather than relying on indirect reporting by others. Surveys to properly capture PRO measures have been under development for more than 2 decades. PROs can include reporting on symptoms and functional status, as well as satisfaction with care and treatment adherence. The potential benefits of PROs for patients include improved management of symptoms and side effects that may result in a higher quality of life and greater satisfaction with care providers. The significance of the patient’s voice in oncology has been demonstrated in studies comparing reporting of symptoms in patients and clinicians. The future of PROs will include technology to help patients capture data and help providers identify meaningful and actionable information.34

One study compared the reporting of health status and symptom severity by patients and their treating physicians for a core set of symptoms related to first-line use of a first-generation tyrosine-kinase inhibitor for chronic myeloid leukemia.35 These patients require lifelong therapy, and optimal management is associated with accurate estimations of symptom severity and health status over time. For all symptoms measured (ie, abdominal discomfort, diarrhea, edema, fatigue, headache, muscle cramps, musculoskeletal pain, nausea, and skin problems),

**COMMUNICATION FUNCTIONS OF INFORMATION EXCHANGE AND FOSTERING RELATIONSHIPS IN CANCER CARE**32

<table>
<thead>
<tr>
<th>Domains of information exchange</th>
<th>Dimensions of fostering relationships</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Content</strong></td>
<td><strong>Physician’s interpersonal manner</strong></td>
</tr>
<tr>
<td>Patients need information about the process of care and actions patients should take to prepare for treatment, manage symptoms, and mitigate side effects</td>
<td>Some of the attributes patients are looking for in clinicians are being accessible, calm, caring, committed, compassionate, engaged, optimistic, respectful, and understanding</td>
</tr>
<tr>
<td><strong>Timing</strong></td>
<td><strong>Patient commitment</strong></td>
</tr>
<tr>
<td>Delays in information extend patients’ uncertainty and contribute to patients’ and family members’ emotional distress</td>
<td>Patients appreciate when the clinician is prepared for the encounter and assists patients in accessing care and offering procedures, visits, or calls at times that meet patients’ needs</td>
</tr>
<tr>
<td><strong>Sufficiency</strong></td>
<td><strong>Knowing the patient</strong></td>
</tr>
<tr>
<td>The perception of patients that they receive too little information is more common than the perception of having too much information, but it is influenced both by individual preferences and the ability to take in information</td>
<td>Patients are comforted by the feeling that clinicians know them for who they really are</td>
</tr>
<tr>
<td><strong>Clarity</strong></td>
<td><strong>Accuracy</strong></td>
</tr>
<tr>
<td>Patients value explanations they can understand</td>
<td>Most patients assume that their clinicians will provide accurate information and have strong negative reactions when they perceive they are given inaccurate information</td>
</tr>
</tbody>
</table>

**Patient-reported outcomes (PROs)**

Any report of the status of a patient’s health condition, health behavior, or experience with health care that comes directly from the patient, without interpretation of the patient’s response by a clinician or anyone else.
patients reported higher severity more often than their physicians. Most often, physician underestimations occurred at the lower end of symptom severity. Physicians also tended to overestimate the overall health status of their patients. Physicians’ failure to note the presence of mild symptoms can have major clinical implications, such as patients’ lack of adherence due to side effects. Introducing PRO measures into clinical practice could improve awareness of symptom burden and outcomes.35

As health care moves from provider-centric to more patient-centric care, a greater emphasis on recognizing patient needs and adapting to those needs will be amplified in the way care is delivered. Tying PROs to provider reimbursement is one way to improve providers’ ability to be more in line with their patients’ needs. Pay-for-performance will undoubtedly be influenced by information on patient experience within the health care setting. Some practices are adding PROs through the patient-centered medical home model.37

Use of technology to improve patient self-management and access to cancer care

Mobile health (mHealth)—the use of any portable or wireless technological device to individually access, coordinate, and share information—has made a rapid advancement in the health care industry,36 with more than 100,000 health apps available in the iTunes and Google Play stores.39 mHealth is designed to enhance communication among patients and providers, as well as augment integration of care processes each step along the care continuum.40

mHealth can be used for numerous health care interventions, from accessing health care information on cell phones to remote monitoring by a health care team.41

mHealth and patient self-management

The use of mHealth plays an important role in empowering patients, giving them the tools needed to manage their condition and any associated side effects and without the need for direct supervision by health care professionals.40 (See the Genentech resource Journey Forward on page 25 for reference to two mobile apps designed to help cancer patients manage their care.)

A recent study tested the theory that symptom self-reporting engages cancer patients as active participants in their health and may improve the experience, efficiency, and outcomes of care.42 The study engaged patients initiating chemotherapy at Memorial Sloan Kettering Cancer Center in New York. Some patients were trained on Symptom Tracking and Reporting (STAR), a Web-based interface previously established as easy to use for cancer patients with high symptom burdens. These patients were invited to self-report using STAR, either via wireless touchscreen tablet computers or a freestanding computer kiosk at subsequent medical oncology or infusion suite visits, only at clinic visits or between visits as well, depending on their experience with computers. Other patients were offered “usual care”—symptoms were discussed and documented in the medical record during clinical encounters between patients and their oncologists. Patients were encouraged to initiate telephone contact between visits for concerning symptoms.42

The study found that health-related quality of life (HRQL) scores improved from baseline to 6 months among more participants who self-reported their symptoms using the remote interface than those reporting their symptoms during their clinical visits; HRQL worsened among fewer

The use of mHealth plays an important role in empowering patients,...

...giving them the tools needed to manage their condition and any associated side effects...

...and without the need for direct supervision by health care professionals.40
Teleoncology involves the use of audiovisual conferencing technology for patients to remotely see cancer specialists. has the potential to overcome many of the physical access barriers to receiving cancer care in rural areas.  

Figure 4. Symptom self-reporting improves health-related quality-of-life scores.  

![Symptom self-reporting improves health-related quality-of-life scores](image)

The authors concluded that finding optimal tools that engage both patients and clinicians in harnessing technology to improve care should be a priority.  

MD Anderson Cancer Center, in collaboration with behavioral health care company Polaris Health Directions, is conducting a pilot study with the hopes of using mHealth to empower cancer patients in their own health and improve patient experience through self-discovery and communication.  

Using an app that runs on a patient’s Apple watch and mobile phone, the program tracks patients’ vital signs and compares them to self-reported data about patients’ mood, distress, and activity levels. Doctors can then assess the data and anticipate potential issues within patients’ experience and intervene sooner in the treatment process. The hope is also that patients can use the program to track the relationship between their activity level and physical and emotional well-being and harness that information to provide a better experience for them throughout the treatment process. In addition, cancer patients can connect with other app users, so they can share experiences and engage others going through the same or similar experiences.  

mHealth and access to care  

The expansion of mHealth provides a needed link between individualized medicine and those without access to care.  

For example, receiving a cancer diagnosis as a resident of a rural area has many challenges. These patients often require extensive and expensive treatments from numerous specialists, many of whom may be a long distance away. In addition, people in rural areas are generally more socioeconomically disadvantaged and less educated than those who live in urban areas, have less access to clinical trials, are more likely to have inadequate discussions about palliative care, and are less likely to receive hospice care.  

Teleoncology, which involves the use of audiovisual conferencing technology for patients to remotely see cancer specialists, has the potential to overcome many of the physical access barriers to receiving cancer care in rural areas. Teleoncology is also increasingly being used to deliver cancer support services, such as psychiatric, nutrition, and palliative care, and has been shown to improve pain and depression symptom scores over usual care received in rural areas.
The teleoncology programs that deliver hospice care through conferencing have reported high patient, nurse, and social worker satisfaction, being especially useful for after-hours consultations, as well as determining whether an at-home visit is needed.43

The Centers for Medicare and Medicaid Services (CMS) have traditionally provided limited reimbursement for this service (patients must be in what is deemed a rural Health Professional Shortage Area or county outside a metropolitan statistical area). However, as data show the benefits of teleoncology, CMS is beginning to loosen restrictions on reimbursement. In addition, 42 states require the service to be covered in their Medicaid program, and 17 states require this of private health plans.43

Use of patient portals in cancer care

A patient portal is a Web site or mobile app through which patients can securely access parts of their medical records and may allow patients to send secure messages to their medical team, request/cancel appointments, refill prescriptions, and pay bills online.46 Portals often are a component of the electronic health record used at a particular hospital or health system and most commonly include46:

- Laboratory reports
- Pathology reports
- Imaging studies
- Medication lists

Researchers from an academic/medical center found that the three most common reasons cancer patients used the portal were to view test results, to respond to messages from clinic staff, and to request medical advice. They found that older and nonwhite patients were less likely to use the portal.46

As the study pointed out, for patients with cancer, these portals may introduce particular considerations.47 Test-result viewing was the most common use by the patient, and the interpretation of such data by individuals without formal medical training outside the context of a health care encounter raises a number of questions. Viewing test results that convey major clinical developments, such as disease progression, might cause psychosocial distress without a clinician's interpretation and support. Patients may become anxious when seeing a result from abnormal radiographic findings or laboratory values that may have no clinical significance. The researchers also found that 37% of patients sent “advice requests” to their providers during evenings and weekends. Since the portal usually is not monitored when the clinic is closed, this could cause confusion and potentially dangerous delays in medical care, if patients expected that their online requests were being viewed and acted upon during those times.47

Increases in portal use can place dramatic demands on clinical staff time and effort; however, as illustrated, some tips can help providers and patients better manage the use of portals.46,47
Team-based care and the oncology medical home

People who have received a cancer diagnosis expect that the many clinicians they encounter across their care continuum will deliver a coordinated and seamless experience. However, oncology care may not always meet this standard, and the responsibility of coordinating care may fall on patients or their caregivers.48

Clear communication and transparent, defined roles and responsibilities can help ensure that care needs are addressed and timely decisions are made. Explicitly helping to transform individual clinicians and separate groups into a team that works together can increase the effectiveness of cancer care.48 In oncology practice, formal efforts are taking place to educate providers in team-based care. In 2014, the Agency for Healthcare Research and Quality funded Team Strategies and Tools to Enhance Performance and Patient Safety (TeamSTEPPS®) as an evidence-based repository of tools to improve communication among multidisciplinary teams. In 2015, ASCO partnered with NCI to launch Teams in Cancer Care Delivery to apply the science of team-based care to oncology.49

Oncology medical homes may improve the care experience for cancer patients. This care delivery system consists of teams of cancer specialists who collectively provide appropriate health care for patients with a cancer diagnosis that is continuous and proactive.50

ASCO projects a shortfall of oncologists in the next decade, with the demand for oncologists outpacing the supply of new oncologists going into clinical practice. Demand for visits to oncologists is expected to see a 48% increase by 2020, whereas the supply of oncologists will rise by only 14%.51

OPERATING PRINCIPLES OF ONCOLOGY MEDICAL HOMES50

- Oriented to the whole person throughout all stages of treatment
- Evidence-based, personalized medical care focused on designing treatment regimens based on current medical evidence for each unique disease presentation, patient-specific factors, and patient choice
- Coordinated and integrated care when and where it is needed and wanted that is culturally and linguistically appropriate across all elements of the complex health system
- Quality and safety, including use of evidence-based medicine, clinical decision support tools, and accountability for continuous quality improvement
- Enhanced access to care, such as open scheduling, expanded hours, and new options for patient communication with the oncology care team

As a result, practices are extending oncology services by promoting a collaborative practice with advanced practice providers (APPs) (ie, nurse practitioners and physician assistants). The results of a recent survey of patients receiving care in a collaborative practice model to assess awareness of and satisfaction regarding APP-delivered clinical services showed high awareness that an APP was providing a clinical service to them and a high degree of satisfaction with care received from APPs.51
Patient-centered management in cancer care

Patient-centered management is an emerging, comprehensive, patient-focused collaboration that includes end-of-life and pain management, education, provider coordination, and patient advocacy. This patient-centered approach implies that selection and coordination of services are done from the broader context of the patient’s perspective and in consideration of the patient’s circumstances.\textsuperscript{52}

To help ease the fear and challenges faced by newly diagnosed cancer patients, some cancer centers today are using patient navigators to help these patients in this confusing environment. The navigators, some of whom are nurses with clinical training, lend emotional support, help with such practical problems as coordinating appointments, and provide information on financial assistance options.\textsuperscript{53}

Patient navigation in cancer care

Many cancer centers have patient navigator programs. Patient navigation is a concept that was conceived more than 2 decades ago and became a prerequisite of accreditation for cancer centers as of 2015, according to a mandate by the American College of Surgeons’ Commission on Cancer.\textsuperscript{54}

The goal of patient navigation is to reduce cancer mortality by eliminating barriers (financial, communications, medical system, psychological, and logistical) to cancer screening, diagnosis, treatment, and supportive care. Patient navigation helps patients between the time of an abnormal finding and resolution of the finding by diagnosis and treatment. Though the initial emphasis was on navigating patients with cancer, the use of patient navigation has been expanded to other chronic diseases.\textsuperscript{54}

Patient navigation has exhibited positive effects. A 2014 study of women of Hispanic/Latino heritage (ie, Latinas) with breast cancer found that a significantly higher percentage of navigated women initiated treatment within 30 and 60 days following their cancer diagnosis. Navigator activities that had the most influence on treatment initiation within 30 days were translation services, transportation services, telephone support, appointment reminders, and accompaniment.\textsuperscript{56}

A patient navigation program was instituted at the University of Alabama at Birmingham Comprehensive Cancer Center. About 40 lay navigators were recruited and trained to provide one-on-one phone and in-person support, teach patients about their treatments, and recognize important symptoms. Based on claims data from 30,589 Medicare patients, the researchers saw a decrease in health care utilization over the 2 years after the program was implemented, including\textsuperscript{53}:  

\begin{itemize}
  \item 18\% Decrease in hospitalizations
  \item 14\% Fewer intensive care unit admissions
  \item 12\% Fewer emergency department visits
  \item $27,288$ Average annual per-patient savings
\end{itemize}

Integrating legal services into patient navigation

Access to legal services can be integrated into patient navigation programs to help improve the quality of life of cancer patients throughout the continuum of care. These services particularly can help low-income cancer patients

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**NURSE NAVIGATORS VERSUS PATIENT NAVIGATORS**\textsuperscript{55}

**Nurse navigators** are clinically trained individuals who are part of the multidisciplinary cancer team and are responsible for identification and removal of barriers to timely and appropriate cancer treatment. The nurse navigator acts as a central point of contact for a patient and coordinates all components involved in cancer care.

**Patient (or lay) navigators** are lay people or social workers who focus on the support aspects of care. In general, they provide assistance with scheduling, financial assistance, psychosocial support, and community support.
deal with legal issues that may negatively affect medical outcomes.\textsuperscript{57}

A New York-based legal organization provides free legal services to cancer patients, as well as other patients with serious or chronic illnesses. Their clients face a variety of legal issues: 61\% had grappled with two or more legal issues. For 78\% of the clients, especially those seeking help with debtor/creditor problems, disability benefits, and job discrimination, their cancer diagnosis had, in effect, created their legal difficulties. Some of the typical legal issues faced by the organization's clients include\textsuperscript{58}:

- Government or disability benefits
- Housing conditions and accessible housing
- Insurance coverage
- Immigration

The organization surveyed 51 clients with cancer and reported on the impact of legal interventions on the quality of their lives\textsuperscript{58}:

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Impact</th>
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<tbody>
<tr>
<td>83%</td>
<td>Reduced worries and stress</td>
</tr>
<tr>
<td>51%</td>
<td>Had a positive effect on their financial situation</td>
</tr>
<tr>
<td>33%</td>
<td>Had a positive effect on their family or loved ones</td>
</tr>
<tr>
<td>23%</td>
<td>Helped them maintain their treatment regimen</td>
</tr>
<tr>
<td>22%</td>
<td>Helped them keep medical appointments</td>
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</tbody>
</table>

Lawyers can be integral in alleviating the myriad of nonmedical issues that so often result from a cancer diagnosis, even though their role is not obvious in what is typically regarded as a health or medical situation.\textsuperscript{58}

\section*{Role of health plan care managers}

Health plan-initiated case management has changed from a means to reduce utilization of services into a more sophisticated model as seen in the patient-centered approach. Case managers’ primary obligation is to act as advocates, providing access to the right care and treatment resources that patients need when they need them, while acting as stewards of scarce and costly treatment resources. Case management can provide consistency of care in a complex and fragmented health care system.\textsuperscript{59}

A 2007 study was conducted of 756 complex patients with life-limiting diagnoses and multiple comorbid conditions — 75\% of whom had cancer — who were covered by a large commercial health maintenance organization from February 2003 through December 2004.\textsuperscript{52} About half (n=358) of the patients received patient-centered management (PCM) with support, such as a registered nurse (RN) case manager, RN team manager, and a physician assigned to the case, compared with 398 who received traditional provider-centered case management services and utilization management. The study was designed to address whether PCM can reduce utilization costs in complex patients compared with case management, without sacrificing lifespan. Among other results, patient-centered management resulted in fewer hospitalizations and more days in hospice care, as well as lower overall costs (Figure 5 on page 18). Patients’ lives were not shortened (26\% of PCM patients died versus 28\% of patients who received usual management).\textsuperscript{52}
Working/employment during cancer treatment

A cancer diagnosis has substantial effects on the economic well-being of affected adults and their families. A recent study estimated that the annual loss of productivity from cancer is between $9.6 and $16 billion among working-age adults in the United States. Although the economic burden is greatest shortly after diagnosis, financial concerns persist years after a cancer diagnosis.60

One way for a cancer diagnosis to impact economic circumstances is through reduced or discontinued employment, though this is affected by cancer type and stage, time since diagnosis, and other factors. One study of the economic impact of a cancer diagnosis showed that for adults who had cancer, there was a decline in employment and earnings from 2 years before to 2 years after the diagnosis.61

The largest share of aggregate lost productivity came from employment disability (eg, unable to work because of illness), followed by missed work days among employed individuals, and lost household productivity (Figure 6).60

The case study on pages 20-21 illustrates how one employer has adopted a program designed by a major academic/medical center to offer a more complete cancer support program to its employees.

Figure 5. Comparison of average per-patient utilization based on 18 months of observations52

<table>
<thead>
<tr>
<th>Service</th>
<th>Patient-centered management</th>
<th>Usual case management</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital admissions</td>
<td>1.2</td>
<td>1.9</td>
</tr>
<tr>
<td>Hospital days</td>
<td>8.5</td>
<td>13.4</td>
</tr>
<tr>
<td>Emergency department visits</td>
<td>1.0</td>
<td>1.5</td>
</tr>
<tr>
<td>Rehabilitation days</td>
<td>3.7</td>
<td>5.8</td>
</tr>
<tr>
<td>Hospice days</td>
<td>3.3</td>
<td>2.4</td>
</tr>
<tr>
<td>Home care days</td>
<td>30.9</td>
<td>36.8</td>
</tr>
</tbody>
</table>

Figure 6. Aggregate annual net productivity loss ranges among adult cancer survivors aged 18 to 64 years60

“My diagnosis was delivered by phone, which is probably not the ideal setting without having any support system to deal with the news. I was probably most afraid of who was going to take care of me. Was I going to be able to work? Was I going to be able to pay my bills? If I were to lose my job, would I be able to afford the insurance that I need? Everything felt totally out of control.”

— Jose, lung cancer survivor4
Cancer patient participation in clinical trials

Clinical trials include the study of surgical, radiation, and drug treatments, offering patients with cancer more chances at disease control after standard options have been exhausted. Successful trials have, in turn, broadened the field of effective treatments available to the wider patient population.\(^8\)\(^,\)\(^6\)\(^2\) Even though cancer clinical trials have brought enormous advances in cancer treatment, few adults diagnosed with cancer each year will get treated through enrollment in a clinical trial.\(^6\)\(^3\) In fact, clinical trial enrollment rates in adult cancer populations have historically been 5% or less, with lower rates among minorities and older patients.\(^6\)\(^4\)

Based on patient surveys and focus groups, most cancer patients lack adequate information about clinical trials; moreover, they expect their treating physicians to provide this information.\(^6\)\(^5\)

Previously denied coverage for participation in a clinical trial, the opportunity to afford clinical trial participation. The provision prohibits health plans or insurance issuers from\(^6\)\(^7\):

- Denying participation in clinical trials
- Denying or limiting coverage of routine patient costs, subject to the plan’s out-of-network coverage policy
- Discriminating against the individual on the basis of participation in a trial

Other costs associated with clinical trials, such as transportation, lodging, loss of income to participate, fear of the unknown, or child care costs, may be obstacles to participation.\(^6\)\(^8\)

Patient adherence to cancer treatment

Traditionally, the treatment of cancer has involved administration of intravenous chemotherapy by medical professionals trained to monitor the patient. Because the site of infusion is often in the hospital or physician’s office, patients and family members can be educated about side effects and other concerns at the treatment location. However, the cancer treatment landscape is changing and today often includes orally administered chemotherapy (OAC) and self-administered subcutaneous injections that are given in the home environment. Patients and/or their caregivers often are responsible for acquisition and administration of these drugs, which carries the inherent risk of medication errors that may compromise the effectiveness of cancer therapies.\(^6\)\(^9\),\(^7\)\(^0\)

Estimates of adherence to long-term oral medication regimens range from 17% to 80%, with an average of approximately 50%.\(^6\)\(^9\)
Mary Bradley is Director of Health Care Planning at Pitney Bowes, a global technology company that leverages physical and digital technologies to power commerce. Ms. Bradley leads a team that is responsible for developing and executing the US health care strategy for the company’s active and retired workforce, which includes designing programs, measuring results, shaping employee communications, and managing the health care budget.

Pitney Bowes, similar to many employers, already has care management programs in place for employees dealing with cancer, including Employee Assistance Programs (EAPs), work-life resources, and access to legal and financial counseling. But, according to Ms. Bradley, Managing Cancer at Work™ addressed a number of gaps in these programs:

- Optimizing the chance for a cure by addressing the issues of the right diagnosis and treatment and place of treatment
- Resources that are focused on employees as caregivers of people with cancer
- Employees’ need for support in balancing time away from work and treatment time
- Managers’ ability to create an effective workplace where they are giving support to employees

In an effort to offer a more complete cancer support program to its employees, Pitney Bowes Inc. teamed up with Johns Hopkins University (JHU) in late 2014 to launch a pilot of the Managing Cancer at Work™ program that the university’s Kimmel Cancer Center developed.

Program description

There are two components to the Managing Cancer at Work™ program—a Web-based program designed to provide employees with comprehensive information about cancer and “live” support from trained nurse navigators employed by JHU. The portal includes:

- Toolkits for supervisors and managers who have employees with cancer or who are acting as caregivers
- Online education through all stages of cancer treatment developed by the Kimmel Cancer Center
- Promotion of cancer screening, education, and early detection programs
- Support for those caring for loved ones with cancer

The program starts with an emphasis on prevention and teaching employees the value of preventive screenings and early warning signs. Once diagnosed with cancer, the program helps employees manage treatment that optimizes the chance for a cure by addressing the issues of the right diagnosis, right treatment plan, and right place of treatment. The nurse navigator will walk each member through the appropriate NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) to give additional support. After the employee or member has gone through the treatment phase, the recovery and survivorship support occurs with both inbound and outbound calls with the navigator, along with the Web site educational material on Life After Cancer Treatment. For employees who are in need of end-of-life support for themselves or family members, the navigators are well-versed in Pitney Bowes’ resources for end-of-life care, available legal support, and hospice coverage.

One of the important aspects of Managing Cancer at Work™ is the way in which it enables employees to better understand their treatment.

“The problem is that cancer is such an emotional diagnosis that people immediately want to get into treatment and don’t even really think about all of the resources that might be available to them through their employer.”

“There is a lot of coaching that does not happen and will not happen unless you bring together somebody who has knowledge of the disease and the needs of the workplace.”
options and to help them manage and normalize their lives during the treatment stage. The dedicated Web site features patient and caregiver videos, explains cancer staging, and offers tips on how to continue working, if desired, during treatment. Employees also can e-mail or call a nurse navigator to get assistance on the practical, physical, and emotional side effects of the disease.

**Advantages of partnering with an academic/medical center**

JHU, because of its affiliated hospital health system that works toward effective heath care delivery, has a better understanding of the failures of the care delivery system and the breakdown in care coordination that often occurs for cancer patients, Ms. Bradley said. For example, employees may not understand that they can continue to work during their treatment or come back to work before their maximum short-term disability concludes.

Supporting employees’ efforts to manage their time away from work can easily be seen with a typical treatment-scheduling process in which a provider fits patients into open slots Monday through Friday. A supportive work environment helps employees schedule treatment that allows them to optimize their work schedule, as well as helps managers maintain productivity during that time. For example, employees can be encouraged to schedule treatments on a Friday so they can experience the worst of the side effects on the weekend, mitigating the need for time off.

**Communicating the program to employees**

In its effort to communicate the benefits of the support program, Pitney Bowes tries to send at least one monthly message about it to employees as a reminder, whether it’s in the form of a testimonial, a blog post, a home mailing, or even the company’s Yammer social media site. But these messages have to be balanced with all other company communications to the workforce, Ms. Bradley said.

An objective of the messaging is to drive awareness of the Pitney Bowes benefits site, which contains links to the JHU support Web site. Because the support is Internet-based, spouses also can go to the site to do more research when they need it.

Many referrals to the JHU navigators also come from Pitney Bowes managers, an indication that the company’s e-mail communications to the workforce have succeeded because managers are reminding employees at the time they need resources that the program is available, Ms. Bradley said.

**Program metrics**

In terms of measuring the success of the program, Ms. Bradley said that Pitney Bowes potentially could see a decrease in the cost of care as a result of better care coordination and use of NCCN treatment protocols. Employee satisfaction is another metric being tracked. The company is hoping to see an increase in preventive screening, an increase in requests for second opinions, and, potentially, a decrease in time away from work due to adverse side effects from treatment.

Pitney Bowes receives reports from JHU on the total number of its employees who have interacted with nurse navigators. The data show about 5% of covered employees have connected with the navigator, and the number of telephone calls between an employee and a navigator range from “two or three all the way up to as many as 25” among patients and caregivers, Ms. Bradley said. Additionally, about 20% of employees have visited the company’s benefits Web site searching for specific cancer information. Among the most popular searches are preventive screening and guidelines for preventive screening.

“I can’t say that every employee who connects with a navigator is going to return to work right away, but the most common questions are about whether they’re going to lose their job and when they’re going to come back,” she said.

“Most support available today is aimed at the patient. This program reminds caregivers that they need to take care of themselves and helps them balance the demands on their lives.”
While patients prefer the convenience of OAC, the self-administration of these agents presents challenges, even though the assumption might be made that adherence—the extent to which patients take medications as prescribed—would be higher due to the seriousness of the illness. However, estimates of adherence to long-term oral medication regimens range from 17% to 80%, with an average of approximately 50%. This includes low adherence rates to adjuvant therapy in breast cancer patients, even though taking adjuvant hormonal therapy for more than 5 years is associated with lower recurrence risk and improved survival. Based on a study that reviewed automated pharmacy records, 32% of 8,769 breast cancer patients enrolled in Kaiser Permanente discontinued tamoxifen therapy. Of those who continued the treatment regimen, only 72% were fully adherent after 4.5 years.

Nonadherence to OAC can manifest for many reasons. Some patients adjust their doses without informing their physician. For example, they may increase the dose due to perceived ineffectiveness, leading to an increase in toxicity, or may decrease the dose because of an actual or perceived toxicity or to delay refilling a costly drug. Physicians who are unaware of a patient’s adherence behavior subsequently may change the dose or therapeutic regimen or order unnecessary diagnostic testing to determine the reasons for changes in the patient’s health status. The patient may even end up hospitalized due to adverse events.

Adherence to an OAC regimen includes more than simply taking the correct amount of medication as prescribed. It also must incorporate other aspects of management in the home setting, including knowing to avoid taking certain additional medications, consuming certain foods, and monitoring contraindicated drugs and drug-drug interactions. In addition, patients with cancer who have comorbid conditions often are prescribed multiple medications for conditions unrelated to their cancer that may be contraindicated, cause drug–drug interactions, exacerbate symptoms, and increase adverse events.

Determining risk for nonadherence
Because nonadherence to OAC may affect treatment success, determining the risk for nonadherence by patients with cancer can help to inform clinical practice. However, the state of the science on assessment and measurement of OAC adherence is poor, and the tools available to assess the risk of nonadherence do not have the specificity needed to determine rates of adherence.

Barriers to adherence
Adherence to oral chemotherapy treatments must take into account the patient’s view of the benefits, risks, and cost of the intervention. The Oncology Nursing Society Oral Adherence Toolkit lists a variety of barriers to adherence with OAC (see box on page 23).

Influence of cost on adherence
The cost of cancer treatment is often a predictor to nonadherence. An exploratory, observational study was conducted of self-reported, treatment-related costs and patient-reported subjective financial burden among 190 insured patients with solid tumors actively receiving chemotherapy or hormonal therapy and seeking copayment assistance. Patients reported altering their lifestyles to afford prescription medications (Figure 7). Copayment assistance applicants were more likely than a comparison cohort of 64 nonapplicants to employ at least one strategy to cope with costs (98% vs 78%).

A study using a random sample of 2008 Medicare Part D data compiled by CMS found that high out-of-pocket (OOP) costs associated with OAC can put Medicare Part D beneficiaries at risk for nonadherence to cancer therapies. Medicare permits high-cost medications to be placed on specialty tiers that frequently use coinsurance, and an overwhelming majority
BARRIERS TO ADHERENCE TO ORAL CANCER THERAPIES

Socioeconomic barriers
- Low language literacy
- Lack of family or social support
- Homelessness
- Lack of health insurance/medication cost/copays
- Limited access to a pharmacy
- Busy work or social lifestyle

Health care system barriers
- Poor provider communication skills
- Poor patient-provider relationship
- Lack of knowledge on adherence
- Lack of reinforcement from health care provider
- Patient information materials written at a high-literacy level

Disease-related barriers
- Asymptomatic
- Severity of symptoms

Treatment-regimen barriers
- Complex regimen
- Lack of quick benefit
- Side effects
- Require substantial behavioral changes

Patient-related barriers
- Physical factors
- Knowledge deficit
- Attitude, confidence, motivation
- Psychological/behavioral/developmental factors
- Perceived benefit of treatment
- Fear of possible adverse effects
- Stress/anxiety/anger
- Alcohol or substance abuse

of patients in the sample were subject to a 25% or larger coinsurance for their OAC. Higher OOP costs for the more expensive drugs studied, which ranged from $22.90 to $37.47 per day, were associated with higher levels of medication discontinuation — between 35% and 70%. A large majority of beneficiaries who used the higher-cost drugs entered the coverage gap at the time of their first prescription fill.

Importance of patient education to adherence

When patients receive self-administered OAC as part of their treatment regimen, they may not receive the same intensive education and monitoring as patients receiving intravenous therapy only. However, patient education is extremely important. Patients must be informed of the purpose of the intervention, along with the expected results and potential side effects they may experience. Patients’ cultural and religious beliefs must be recognized and respected, as well as language deficits and poor literacy. Poor communication with the health care team and patient dissatisfaction with care also contribute to poor adherence.
Role of specialty pharmacies in medication adherence

Specialty pharmacies (SPs) have assumed a larger role in disease management for cancer patients, particularly in light of the arrival of new oral oncology treatments. SPs have become a distribution channel for various agents, including self-injectable supportive care agents, oral anticancer agents, and, in some instances, parenteral chemotherapy or biologic agents.78

COMPONENTS OF COMPREHENSIVE PATIENT AND FAMILY EDUCATION70

- Address the dose, frequency, and timing of dosing, and what to do if a dose is omitted
- Instruct on side effects and symptom management and what to do if an adverse effect is encountered
- Offer written aids and explanations of the importance of adherence, along with the possible ramifications of nonadherence
- Schedule a time to discuss detailed drug information at another time than when patients are receiving information about their diagnosis, prognosis, or proposed treatment options
- Suggest the use of pillboxes, calendars, diaries, alarms, and other tools to support adherence
- Monitor adherence and persistence on a regular basis
- Schedule follow-up visits that are convenient and efficient for the patient

As oral cancer treatments become more frequently used, SPs are building stronger relationships with oncologists to provide for the special needs of their cancer patients. Changes in health plan benefit designs—with drugs previously covered under the Medicare Part B medical benefit moving to the Part D prescription benefit—have resulted in creating a larger medication portfolio that requires a high level of alert management.78

The growth in oral oncology products also has prompted physicians to begin dispensing them from their offices and clinics. These practice-affiliated pharmacies serve as “closed-door” pharmacies and provide services only to the practice’s patients. In-office dispensing enables the physician to have more control over treatment and creates an additional revenue source for the practice.79 Under whatever circumstances patients receive pharmacy care, the focus should be on patient-care issues and extend beyond product-specific issues.80

Summary

The Patient Voice Across the Cancer Care Continuum: Treatment emphasizes the importance of incorporating the patient voice during the treatment phase of the cancer care continuum, including:

- Focusing on shared decision making and empowering patient activation
- Understanding patient perspectives on active cancer treatment, including using patient-reported outcomes to understand the patient journey
- Using emerging technology to enhance patient self-management
- Adopting team-based care to deliver a coordinated and seamless experience for patients
- Encouraging patient-centered management, which emphasizes patient preferences based on their individual cancer experience
- Considering the needs of patients and/or their caregivers who are working during active cancer treatment
- Adequately informing patients about clinical trials
- Understanding the challenges inherent in adherence to cancer treatment regimens

Insights into the patient voice through other phases of cancer care are further explored in two companion reports in this series: The Patient Voice Across the Cancer Care Continuum: Screening, Diagnosis, and Prehabilitation and The Patient Voice Across the Cancer Care Continuum: Survivorship, End of Life, and Other Cancer Care Issues.
Appendix/Resources

**Genentech Resources**

Below is a sampling of initiatives and resources sponsored or supported by Genentech to assist patients, family caregivers, clinicians and other stakeholders throughout the cancer care continuum.

**Care Management Workshops and Resources**


Each interactive session in the Care Management Workshop Series provides an opportunity for care managers to learn and discuss key patient issues and challenges. Experts lead the 1- to 2-hour workshops, which can be attended live or via webcast. In oncology, the following workshop topics are available: Foundations of Oncology, Palliative Care, Psychosocial Issues in Cancer Care, and Cancer Survivorship. The objectives of the care management workshops are to equip care managers with the skills to better guide and advocate for patients during their treatment journey and to improve the efficiency and quality of care for patients living with chronic and advanced illness.

**Journey Forward**


Journey Forward was developed in response to the 2005 Institute of Medicine report *From Cancer Patient to Cancer Survivor: Lost in Transition*, which revealed poor cancer care coordination and a deep lack of awareness about survivorship care needs among cancer survivors. A unique collaboration involving Genentech began in 2008 to develop tools for oncology professionals and primary care physicians, as well as cancer survivors, to address needs for coordinated follow-up care once active treatment comes to an end. These include free survivorship care plan builder software for clinicians, a medical history builder resource for survivors, a directory of survivorship resources and a searchable online library of survivorship articles available from the Web site. Included in the patient tools are two mobile phone applications (apps) — the Self-Care app and the My Care Plan app.

**Love Your Colon**


Love Your Colon, founded in 2007, is an initiative designed to increase awareness of colorectal cancer and the importance of screening. The goal is to increase screening rates and decrease the number of colorectal cancer-related deaths. Through customizable resources on the Web site, communities at-large, health care providers, employers, and payers can educate and encourage their citizens, patients, employees, and members to take action against colorectal cancer.

**General Resources**

Below is a sampling of initiatives and resources sponsored by public and private organizations to support patients, family caregivers, clinicians and other stakeholders throughout the cancer care continuum. Genentech does not endorse these organizations nor the views they express or the products/services they offer. These listed organizations below are provided solely for information purposes. Genentech does not control or guarantee the accuracy, relevance, timeliness or completeness of information provided by these organizations.

**Cancer and Careers**


Cancer and Careers helps nearly 300,000 people each year — online, in print, and in person — by providing valuable information and resources via expert advice, interactive tools, and educational events.

**CancerCare®**


Founded in 1944, CancerCare is the leading national organization providing free, professional support services and information to help people manage the emotional, practical, and financial challenges of cancer.

**Cancer Experience Registry**

[https://www.cancerexperienceregistry.org/](https://www.cancerexperienceregistry.org/)

The Cancer Experience Registry is a grassroots effort to engage participants who have been impacted by cancer to answer questions about their social and emotional experiences and needs throughout their cancer journey. It is a research project driven by people living with cancer and their caregivers.

**Cancer Financial Assistance Coalition (CFAC)**

[www.cancerfac.org](www.cancerfac.org)

CFAC is a coalition of financial assistance organizations joining forces to help cancer patients experience better health and well-being by limiting financial challenges.

**Cancer.Net**


Cancer.Net provides timely, comprehensive, oncologist-approved information from the American Society of Clinical Oncology (ASCO), with support from the Conquer Cancer Foundation. Cancer.Net brings the expertise and resources of ASCO to people living with cancer and those who care for and about them to help patients and families make informed health care decisions.
Cancer Support Community (CSC) (http://www.cancersupportcommunity.org/)
As the largest professionally led, nonprofit network of cancer support worldwide, the CSC is dedicated to ensuring that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community. CSC achieves its mission through three areas: direct service delivery, research, and advocacy. The organization includes an international network of affiliates that offer the highest quality social and emotional support for people impacted by cancer, as well as a community of support available online and over the phone. The Research and Training Institute conducts cutting-edge psychosocial, behavioral, and survivorship research. CSC furthers its focus on patient advocacy through its Cancer Policy Institute, informing public policy in Washington, DC, and across the nation.

Coping® With Cancer (http://copingmag.com/cwc/index.php/about/about_coping/about_us/)
The Coping with Cancer Web site is a complete online experience that educates and inspires. It is presented in a warm and friendly, easy-to-use format, and provides information by specific cancer type, general knowledge about living with cancer, and wellness and inspirational topics.

Global Resource for Advancing Cancer Education (GRACE) (cancergrace.org/)
GRACE provides expert-mediated information on current and emerging cancer management options in order to empower patients, caregivers, and health care professionals to become direct partners in cancer care.

Critical Mass: The Young Adult Cancer Alliance (criticalmass.org)
Critical Mass is a community-powered advocacy organization whose mission is to transform the care and treatment of young adults with cancer.

Informed Medical Decisions Foundation (http://www.informedmedicaldecisions.org/)
The Informed Medical Decisions Foundation, now a division of Healthwise, has been working to advance evidence-based, shared decision making since 1989. They believe the only way to ensure that high-quality health care decisions are being made is for fully informed patients to participate in a shared decision-making process with their clinician. Through research and advocacy efforts, the foundation is dedicated to helping people make better health decisions.

MetaCancer Foundation (metacancer.org)
The MetaCancer Foundation provides resources and support for metastatic cancer survivors and their caregivers. MetaCancer encourages dialogue among those with very different types of metastatic cancer (breast, prostate, colorectal, ovarian, bladder/urinary, skin, lung, testicular, among others), even though respective treatment protocols and medical issues may seem to have little in common with each other. The common bonds are the psychological and emotional realities faced by anyone living with metastatic cancer. MetaCancer provides resources for everyday living, opportunities for creative reflection, and possibilities for you to “go meta”: to live beyond your diagnosis right now with strength, grace, and peace.

Mobile Resources Selected by the Memorial Sloan Kettering Library: Patients & Caregivers (http://libguides.mskcc.org/c.php?g=245150&p=1632654)
Mobile resources are categorized as follows: Health-U.S. Government, About Cancer, Quit Smoking, Medication-Related Resources, Diet and Fitness, Signs and Symptoms, Emergencies and First Aid, Resources to Feed the Mind, Local Amenities and Other Useful Health sites and apps.

My Cancer Circle (http://mycancercircle.lotsahelpinghands.com/)
My Cancer Circle, powered by Lotsa Helping Hands, is a simple online tool that helps organize the community of people who want to help caregivers of patients with cancer. It coordinates their efforts to more efficiently support the caregiver and the loved one facing cancer. My Cancer Circle coordinates volunteer activities, including meals, transportation to medical appointments and other tasks; provides a private space where community members can offer words of support and encouragement and where caregivers can post updates and information about their loved one; and schedules offers to give caregivers a break or to do something special for them.

National Cancer Institute (NCI) (http://www.cancer.gov)
NCI offers free, credible, current, comprehensive information about cancer prevention and screening, diagnosis and treatment, research across the cancer spectrum, clinical trials, and news and links to other NCI Web sites. The Web site contains excellent resources for both patients and caregivers.

National Cancer Legal Services Network (NCLSN) (www.NCLSN.org)
NCLSN promotes access to health care and seeks to increase the availability of legal services for people living with cancer, their families, and caregivers. Through direct work, educational efforts and advocacy, this multidisciplinary coalition helps to alleviate the legal and economic consequences of cancer so that those affected may focus on their medical care and quality of life. The NCLSN supports the efforts of individuals and organizations focused on meeting the legal needs of the cancer-affected community. It augments the voice of disparate services, creates a forum for established and nascent legal advocacy groups, and facilitates the development of similar programs.
National Coalition for Cancer Survivorship (NCCS) (http://www.canceradvocacy.org/)
NCCS’ mission is to advocate for quality cancer care for all people touched by cancer. Founded by and for cancer survivors, NCCS created the widely accepted definition of survivorship and defines someone as a cancer survivor from the time of diagnosis and for the balance of life.

National Colorectal Cancer Roundtable (NCCRT) (http://nccrt.org/)
NCCRT, established by the American Cancer Society and the Centers for Disease Control and Prevention in 1997, is a national coalition of public, private, and voluntary organizations and invited individuals dedicated to reducing the incidence of and mortality from colorectal cancer in the United States, through coordinated leadership, strategic planning, and advocacy. The NCCRT campaign “80% by 2018” aims to reach 80% screening rates for colorectal cancer by 2018, and has over 1,000 organizations pledging support across the United States.

NCCN Patient and Caregiver Resources (nccn.org/patients)
NCCN Guidelines for Patients® are translations of the NCCN Guidelines® and are designed to help patients with cancer talk with their physicians about the best treatment options for their disease. This Web site provides state-of-the-art cancer treatment information in easy-to-understand language.

PatientsLikeMe® (https://www.patientslikeme.com/)
Members of PatientsLikeMe contribute directly to research through data sharing to advance understanding of the disease in a way that can accelerate discovery and improve care. Patients have the opportunity to share both personal stories and health data about their conditions to help put their disease experiences in context and find answers to the questions they have. In addition, PatientsLikeMe’s Open Research Exchange (https://www.openresearchexchange.com/) has created an open platform for developing, validating, and sharing health-outcome measures that better reflect patients’ experiences with a disease, and assess health and quality of life in ways that matter to patients.

Preparatory Education About Clinical Trials (PRE-ACT) (http://www.cancer.net/navigating-cancer-care/how-cancer-treated/clinical-trials/pre-act)
This educational program is designed to provide general information about clinical trials. PRE-ACT was developed with support from the National Cancer Institute to help cancer patients better understand what clinical trials are and how they work.

Reimagine (https://reimagine.me/)
Reimagine is a powerful collection of tools that are designed to help everyone in the cancer community feel better, all based on The Seven Pillars of Personal Strength™. The program consists of 10 self-paced online modules with more than 100 activities, videos, and live sessions. The Core Program will help patients, survivors, friends, and family learn a proven set of skills for navigating the challenges of cancer and life. It is an essential component of any Survivorship Care Plan and a powerful tool for people who score a four or above on the Distress Thermometer.

Triage Cancer (http://triagecancer.org/)
Triage Cancer works to address cancer-related health disparities through the delivery of cancer survivorship education, particularly information related to accessing care. Information is tailored to specific cancer-community audiences, including childhood cancer survivors and their parents, adolescents and young adults, seniors, newly diagnosed patients, individuals who have completed treatment, individuals with advanced disease, caregivers, advocates, and health care professionals.

US Preventive Services Task Force (USPSTF) (http://www.uspreventiveservicestaskforce.org)
USPSTF develops recommendations for preventive services, such as screening tests, counseling services, and preventive medications, based on a review of high-quality scientific evidence.

Watson Health Initiative
IBM and the American Cancer Society are launching a new partnership that will combine the power of Big Blue’s cognitive computing platform, Watson, with the wealth of cancer research and patient support services provided by the nonprofit organization. The two organizations will combine forces to create a service that will provide cancer patients, survivors, and caregivers with personalized access to vetted cancer resources.

WhatNext (https://www.whatnext.com/)
The American Cancer Society has a new online tool called WhatNext that has unique, patent-pending technology to connect people based on their specific diagnosis and medical experiences. On WhatNext, people can easily access relevant firsthand experiences posted by others in similar circumstances, share their experiences, and get answers to their questions. Rare Patient Voice, LLC, has a partnership with WhatNext, which makes available 32,000 cancer patients and caregivers for qualitative and quantitative research.
References:


Issues in Focus:
The Patient Voice Across the Cancer Care Continuum

A series of informational white papers provided by Genentech, South San Francisco, CA

Produced by Emron, Wayne, NJ
www.emron.com
Issues in Focus
The Patient Voice Across the Cancer Care Continuum
Survivorship, End of Life, and Other Cancer Care Issues
Disclosure

The content of this report was prepared by Emron on Genentech’s request with the guidance of an editorial board and is based on published literature. Statements and opinions contained in the report do not necessarily reflect those of Genentech or the editorial board.
The Patient Voice Across the Cancer Care Continuum
Survivorship, End of Life, and Other Cancer Care Issues

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Suggested Citation

The Patient Voice Across the Cancer Care Continuum: Survivorship, End of Life, and Other Cancer Care Issues. South San Francisco, CA: Genentech; 2016.

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In Memoriam

This edition is dedicated to the memory of Jan Gbur who served as Emron’s project manager for this report. Her voice was silenced by a short battle with cancer. She is missed and fondly remembered.
Introduction

Many Americans know all too well the devastation cancer can bring. Cancer spans all ages—from children to adolescents/young adults, working-age adults, retired adults, and the frail elderly—and affects people across the socioeconomic spectrum and from all ethnicities and cultures. The American Cancer Society estimates that nearly 1.7 million new cancer cases will be diagnosed in the United States in 2016, and that more than 595,000 Americans will die from some form of the disease.

The patient experience with cancer is at the forefront of the public eye, especially with a new, national “Moonshot” initiative to eliminate cancer instituted in 2016. This $1 billion initiative will focus on making the most of federal investments, targeted incentives, private-sector efforts from industry and philanthropy, patient-engagement initiatives, and other mechanisms to accelerate the development of new cancer detection methods and treatments.

CANCER PATIENTS BY THE NUMBERS

- **1,685,210** Estimated new cases of cancer in 2016
- **23%** Drop in cancer death rate from 1991 to 2012 due to smoking reduction and improved early detection and treatment
- **Nearly 14.5 million** Number of cancer survivors in 2014

CANCER SURVIVORS LEND THEIR VOICES

Leaders representing a diverse group of stakeholders from across the United States came together at Genentech’s corporate campus in South San Francisco, California, to attend the 2016 Genentech Oncology Institute on May 4–5, 2016. This year’s program focused on the cancer patient journey through prevention, diagnosis, treatment decisions, and outcomes. Cancer survivors shared their experiences through video vignettes during the event. Commentary from these vignettes regarding the following survivors are included in this report.

Cancer survivor profiles

- **Mia is a 47-year-old breast cancer survivor**
  - She describes herself as being healthy and active and following a vegan diet. She started dancing at the age of 5 and has been a fitness instructor for over 30 years. With a strong family history of breast cancer, Mia shares her thoughts about proactive breast cancer screening and patient decision making.

- **Glenn is a 63-year-old chronic lymphocytic leukemia (CLL) survivor**
  - He describes himself as a significantly overweight couch potato until the age of 47 when he took up and became addicted to running. He was diagnosed with CLL as a result of a routine physical exam. After receiving his diagnosis on the telephone, Glenn shares his experience with gathering timely information from Web sites and chat rooms.

- **Jose is a 55-year-old lung cancer survivor**
  - He speaks about his emotional struggles, concerns about his job and ability to work, and what he has learned from other cancer survivors.

- **Jennifer is a 31-year-old ovarian cancer survivor**
  - She was diagnosed with ovarian cancer at age 17 during a pregnancy. She speaks about her trust in her doctors, fears of seeming weak, and the need to be strong for her family.
Due to the nature of the disease, cancer’s influence is far reaching and often calls upon the support of family members as unpaid caregivers. The experience of cancer can also strain or negatively impact patients’ socioeconomic status due to the financial burden of cancer treatments, loss of work, and long-term consequences of cancer. In addition, the physical and psychosocial effects of cancer may linger long after active treatment ends.

A 20% improvement in the 5-year relative survival rate for all cancers from 49% in 1975 to 69% in 2011 means that more people are living with cancer as a chronic disease. Survival is improving due to advanced diagnostics, less toxic and more targeted therapies, the availability of second- or even third-line therapies, and improved surgical and radiation therapy techniques.

Cancer is a complicated disease steeped in complex terminology, and having cancer is not like having any other kind of illness. Cancer is an experience that only those who have had cancer seem to truly understand; yet, people do not have uniform or parallel responses to having cancer. A cancer patient’s needs and experience change dramatically over the course of cancer care, and best practices for addressing these needs vary significantly across the patient journey.

In order to provide quality of care and life, it is important to understand the attitudes, aptitudes, needs, and experiences of cancer patients so that providers can effectively communicate with them, seek their involvement in decision making and goal setting, and support living with cancer.

The Patient Voice Across the Cancer Care Continuum, provided in three parts, is the fourth installment in the Issues in Focus series sponsored by Genentech. Its goal is to take a closer look at cancer through the perspective of the patient — commonly called the “patient voice” — across the…

…continuum of cancer care, which includes screening, diagnosis, treatment, survivorship, end-of-life care, and other cancer care issues.

The third part, The Patient Voice Across the Cancer Care Continuum: Survivorship, End of Life, and Other Cancer Care Issues, explores patient perspectives on the transition from active treatment to survivorship and, in some cases, preparing for the end of life. Other topics that significantly impact the patient journey are discussed, such as the role of caregivers, the cost of cancer care, and challenges of cancer care across the age continuum. The first and second parts, The Patient Voice Across the Cancer Care Continuum: Screening, Diagnosis, and Prehabilitation and The Patient Voice Across the Cancer Care Continuum: Treatment, expand our understanding of the patient voice, as patients navigate through other phases of the cancer care continuum.
By 2026, it is estimated that the population of cancer survivors will increase to 20.3 million.\(^{15}\)

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**SURVIVORSHIP**

Patient perspectives on survivorship

In addition to prevention, diagnosis, and treatment, the National Cancer Institute designates survivorship as a distinct phase of the cancer care continuum.\(^{11}\) A growing number of patients are surviving for longer periods, making cancer a chronic disease. These patients are often confronted with a myriad of other challenges that have physical, psychosocial, and financial implications, and which can impact their quality of life and add to higher levels of anxiety and uncertainty about the future.\(^{7}\) An interview with Lidia Schapira, MD, a recognized expert in the area of survivorship care, offers insights into this aspect of cancer care (see pages 6-7).

**END-OF-LIFE CARE**

Preparing for the end of life

When a person reaches a point, usually late in their illness, when disease-directed therapies are no longer helping, or when their burden outweighs their benefit, it becomes appropriate to use hospice care.\(^{12}\) One definition of hospice is a service delivery system that provides palliative care for patients who have a limited life expectancy and require comprehensive biomedical, psychosocial, and spiritual support as they enter the terminal stage of an illness or condition. Hospice also supports family members coping with the complex consequences of illness, disability, and aging as death nears.\(^{13}\) Many health care professionals and patient advocates hope recent debates over physician-assisted suicide will increase awareness of palliative and hospice care.\(^{14}\)

The number of patients and families served by hospice care has steadily increased over the past several years, although the percentage of cancer patients among all patients receiving hospice care has declined since the 1970s, when hospice care was initially established and cancer patients made up the largest percentage of admissions. Cancer was the primary diagnosis of 36.6% of the estimated 1.7 million patients who received hospice care in 2014.\(^{16}\)

In 2014, about half of hospice patients received care for 14 days or less (Figure 1). The total number of days that a hospice patient receives care can be influenced by a number of factors, including disease course, timing of referral, and access to care.\(^{16}\)

Figure 1. Percentage of hospice patients by length of service in 2014\(^{16}\)

<table>
<thead>
<tr>
<th>Number of days</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;7</td>
<td>35.5%</td>
</tr>
<tr>
<td>8–14</td>
<td>14.8%</td>
</tr>
<tr>
<td>15–29</td>
<td>12.9%</td>
</tr>
<tr>
<td>30–89</td>
<td>17.8%</td>
</tr>
<tr>
<td>90–179</td>
<td>8.7%</td>
</tr>
<tr>
<td>180+</td>
<td>10.3%</td>
</tr>
</tbody>
</table>

> “Once you have had cancer, you are always a survivor, and you are always thinking that it could come back. Today, I am different because I do not take things for granted. I know that I can tackle whatever is put in front of me. I’ve also learned that from other survivors. I’ve seen perseverance, strength, and grace in so many people.”

— Jose, lung cancer survivor\(^{4}\)
Many health care professionals and patient advocates hope recent debates over physician-assisted suicide will increase awareness of palliative and hospice care. The majority of patient care is provided in the place the patient calls “home,” which can include nursing homes and residential facilities in addition to private residences. In 2014, 58.9% of patients received care at home and 31.8% received care in a hospice inpatient facility. The preferences of patients with a terminal illness for the location of death may differ and can vary throughout the course of their illness, even if a preference for a home death is expressed at some point. Some patients with cancer change their minds about where they would like to die as their disease progresses. Worsening symptoms, such as severe pain, hemorrhage, or agitated delirium, and limited professional or informal care at home may result in the patient feeling safer in an institutional setting.

The fact that patients must give up insurance coverage for disease-directed treatment in order to access hospice is a key reason why the median length of stay in hospice, which can be up to 6 months, is only about 3 weeks and declining over time. The Medicare Choices Model, under the Centers for Medicare and Medicaid Services (CMS), provides a new option for Medicare beneficiaries to receive hospice-like support services from certain hospice providers while concurrently receiving services provided by their curative care providers. The model will be tested at 140 Medicare-certified hospices for 3 to 5 years, beginning in January 2016.

Caregivers of patients at the end of life
Caregivers of patients with cancer often exhibit extraordinary commitment, provide incalculable value, and face substantial burdens in carrying out the caregiver role. Alleviation of caregiver distress needs to be taken into consideration when dealing with end-of-life care. Palliative and/or hospice health care providers may need to navigate the complex nature of family dynamics, relationships, and belief systems, which can influence patient care at the end of life. It is important that family members understand, and are prepared for, what is meant by end-of-life care within the context of a palliative care or hospice care program.

A recent study of family members of older patients with fee-for-service Medicare who died of lung or colorectal cancer found that earlier hospice enrollment, avoidance of intensive care unit admissions within 30 days of death, and death occurring outside the hospital were associated with family members’ perceptions of better end-of-life care (Figure 2).

Figure 2. Comparison of circumstances under which family members reported excellent end-of-life care

<table>
<thead>
<tr>
<th>Family members reported excellent end-of-life care more often for patients:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Who received hospice care for longer than 3 days (58.8%)</td>
</tr>
<tr>
<td>VS</td>
</tr>
<tr>
<td>those who did not receive hospice care or received 3 or fewer days (43.1%)</td>
</tr>
</tbody>
</table>
SURVIVORSHIP IN FOCUS: THE KEY IS GETTING AN EARLY START ON PATIENTS’ NEEDS

Lidia Schapira, MD, is a medical oncologist and Director of Cancer Survivorship Research at the Stanford Cancer Institute/Stanford Medical School. In May 2015, she was appointed Editor-in-Chief of Cancer.Net, the American Society of Clinical Oncology’s (ASCO) patient information Web site. She has served as Associate Editor of Psychosocial Oncology for more than a decade and is recognized as an expert on doctor-patient communication.

What cancer survivorship care needs to become more effective and comprehensive is relatively straightforward: better organization and a more timely approach. That is the sense of Dr. Lidia Schapira, a medical oncologist who has been working in this area for more than 25 years.

Dr. Schapira, who defines survivorship as a phase of care that begins at the patient’s initial diagnosis, advocates for early intervention and patient analysis as the most appropriate way to assess various risks and complications and to begin organizing a personal care plan. This includes a “risk stratification” approach that helps to identify patients most in need of support and to target them as early as possible in their cancer experience.

Dr. Schapira believes this care model is in sync with the precision medicine concept in which genomic testing fosters personalized treatment for cancer patients.

The optimal survivorship care programs are driven by an understanding of the unique needs of each survivor and the impact this has on the intensity of care. For example, survivors who are at high risk of physical side effects following treatment may need intense rehabilitation, whereas those at risk for psychological side effects are more likely to require psychosocial support.

Elements of a survivorship care program

The key elements of a survivorship care program are:

- screening
- surveillance
- psychosocial services
- counseling
- medical follow-up

It is the follow-up piece, however, that lacks consensus among the community of clinicians, advocates, and thought-leaders regarding the roles different health care professionals should champion in the care plan, Dr. Schapira said. Some aspects of follow-up care are handled better by clinicians from the cancer team, while other aspects can be done by well-informed primary care physicians or nurse practitioners, as long as they understand that this is a population that perhaps deserves special attention in many respects.

Supporting patients after active treatment

Dr. Schapira noted that, in many instances, the bond between oncologist and patient are “special and sacred and should be respected.” But once active treatment is over, it is important for the patient to resume a relationship with the primary care physician, who is better suited to following the patient over time, or with another member of the cancer team who is available or who specializes in surveillance.

The important consideration for health care professionals is to move carefully and to strive to help survivors so they emerge feeling whole again and, perhaps, even strengthened by the experience. Many patients, after being
treated for cancer, develop either psychological distress, anxieties in the form of post-traumatic stress disorder, or even depression. Patients are also dealing with the fear of recurrence or uncertainty about the future. For many patients, the treatment of cancer has affected their job performance and may lead to loss of work. Others find that important relationships may end or their role within the family has changed. The cancer experience may produce losses on multiple levels, and those have to be dealt with and acknowledged. “It is not like patients can just snap their fingers and go right back to where their life was,” Dr. Schapira noted.

Among the physical and medical issues that are often prevalent among cancer survivors as a result of surgery are issues related to body image and/or disfigurement or limitations in movement. For breast cancer survivors, for example, these issues often affect their upper extremities, limiting arm movement. Survivors often express concern about swelling or pain in the surgery area or chest wall for women who have had breast reconstruction.

Fatigue also seems to be pervasive among cancer patients, and it is a nagging fatigue that does not improve with rest. This can last a year or longer, Dr. Schapira said. Many survivors are concerned with neuropathy, which is a common complication of some chemotherapy drugs used to treat breast cancer. Women who experience neuropathy also often have lingering numbness or tingling in their toes and fingers that affects everyday function and quality of life.

Dr. Schapira said that many of her visits with cancer survivors are spent “going through the inventory of different physical symptoms and the strategies for improving them.” The symptoms include anxiety, cancer-related fatigue, sexual dysfunction, or even the “fogginess” and cognitive changes that may occur as a result of the cancer treatment experience.

**Developing a care plan**

Even with a greater focus on survivorship care, Dr. Schapira said she believes only a small number of cancer patients are receiving a survivorship care plan upon completing their treatment. These care plans are not standard practice yet even though organizations, such as ASCO, offer templates for care plans on their Web sites.

Another barrier to survivorship care is the dearth of formal programs that offer instruction to health care professionals who want to become more skilled in this area. There are efforts in and around Boston to develop such courses for primary care physicians, and Dr. Schapira believes these efforts will become more common nationwide. Major cancer centers are the likely choice to lead this effort and to educate health care professionals across the care spectrum “so that everybody can become better informed and be part of this,” she said.

Dr. Schapira also sees a role for new technology to enhance survivorship care. “We shouldn’t be afraid to use new technology to help solve this problem,” she said. “It’s possible we can find a way to capture a lot of information that occurs while a patient is being treated and then put it into a document that’s generated as the cancer treatment evolves.” This document can be edited and finalized at the end of the cancer experience “rather than thinking that a survivor care plan is something that begins when active therapy is over.”
Family members reported that patients who received hospice care for longer than 3 days died in their preferred location (72.8%) versus those who did not receive hospice care or received 3 or fewer days (40.0%).

**OTHER CANCER CARE ISSUES**

Caregivers play an important role in cancer care

Families matter in the care of patients with cancer. They provide the context in which patients adapt to cancer, especially since it is a potentially life-threatening disease with an unpredictable trajectory and varying degrees of supportive care needs. Family caregivers, also referred to as informal caregivers or unpaid caregivers, play an integral part in the management of the cancer, as they provide support in physical, psychological, spiritual, and emotional areas.

The preferences of patients with a terminal illness for the location of death may differ and can vary throughout the course of their illness, even if a preference for a home death is expressed at some point. Some patients with cancer change their minds about where they would like to die as their disease progresses.

They may be spouses, partners, children, relatives, or friends who help the patient navigate daily living and health care needs at home.

Some families, however, may have suboptimal internal relationships, which may lead to communication difficulties. Family meetings and/or designating a specific family member as the primary communicator with the oncology team can help to ameliorate some of the communication difficulties. Some health care professionals believe that it is advisable for clinicians to request the family to appoint a spokesperson through whom information can be delivered.

More women than men become caregivers, most are related to the patient, and most caregivers are 55 years or older. Seeking their cooperation and enlisting them in the care process, beginning at diagnosis, are key ingredients to help patients effectively manage their cancer. Oncology teams recognize this and try to include these caregivers in treatment planning, decision making, and implementation.

**VARIOUS CAREGIVER RESPONSIBILITIES**

- Integrate new medical information and learn new illness-related terminology
- Work through the health care system for the patient
- Accompany the patient to medical appointments
- Schedule medical visits and plan travel to and from the visits
- Administer medications and help manage side effects
- Keep track of insurance matters
- Take on many of the patient’s household duties
- Arrange for home care
- Feed, bathe the patient, and dress wounds
- Keep other family members and friends informed of patient’s health
Caregiving across the cancer care continuum

The caregiver’s role changes as the patient’s needs change during and after cancer treatment. New challenges present themselves at key times in the care of patients with cancer: at diagnosis, during treatment at the hospital, when the patient needs care at home, after treatment ends, and at the end of the patient’s life.5

Diagnosis and active treatment: During the active treatment phase, caregivers report difficulties in juggling the competing demands of providing emotional and tangible support to patients while meeting the ongoing obligations of home, work, and family.5

Transitions of care: Transitions between care settings are particularly stressful for both patients and caregivers.5 As patients transition from active treatment, caregivers’ responsibilities include coordination of care and monitoring of late effects, recurrence, or disease progression.24

Post-treatment: Caregivers must establish a “new normal” following treatment completion, which will vary based on the patient’s disease trajectory.24 Persistent psychological distress and role-adjustment problems experienced by caregivers have been reported up to a year after patients complete treatment.5

End of life: Caregivers of patients at the end of life have been shown to have lower quality-of-life scores and health scores than during active treatment.5

Bereavement: How caregivers cope with loss of a loved one from cancer is influenced by the cancer experience; the manner of disease progression; their cultural and religious beliefs, coping skills, and psychiatric history; the availability of support systems; and their socioeconomic status.25

The relationship between the caregiver and the patient affects the outcome of any decision making.5 While people may differ in opinions, it is important to disseminate accurate information and evidence so that those opinions are based, to the greatest extent possible, on the facts as they are known and a candid assessment of their limits.13

Caregiver stress

Caregivers often display extraordinary commitment, provide incalculable value, and face various burdens in carrying out the caregiver role.13 Caregivers have their own emotional responses to a patient’s diagnoses and prognoses, and they may require coaching and emotional support separate from that offered to the patient. Caregiver roles and burden are profoundly affected by a patient’s prognosis, stage of illness, and goals of care.21

How well a caregiver fulfills the role may depend on his or her preexisting relationship with the patient and the level of agreement between caregiver and patient. Disagreements and conflicts can complicate decision making and affect treatment choices. In addition, disagreements within the family about the most appropriate treatment options for the patient can cause excessive stress for both parties, resulting in diminished quality of life.23

“Losing my hair was probably the hardest part for me, because I was 17, and I felt like I thought I was invincible. I was afraid of seeming weak. I felt like I needed to be strong for my mom, sister, aunt, baby, and everyone. And I did not want to ever feel like I wasn’t in control of my destiny, and wasn’t in control of getting better.”

— Jennifer, ovarian cancer survivor4
Addressing unmet needs
Caregivers’ needs, resources, and capabilities are influenced by multiple factors, including gender, age, culture, education, economics, and geographic location. Residual effects from disease and treatment, late effects, and altered household and family roles, along with altered communication patterns adopted during treatment, remain a source of anxiety for caregivers as they seek to reinstate work and secondary roles. Caregivers assist patients with persistent symptoms, emotional distress, medical problems, social needs, need for information, and coordination of care services. Caregivers report using financial resources, selling homes, taking out loans, and even declaring bankruptcy as a result of expensive care.

Recommendations for addressing caregiving challenges include:
- Improving the estimation of the prevalence and burden of informal cancer caregiving
- Advancing the development of interventions designed to improve outcomes for cancer patients, caregivers, and patient-caregiver dyads
- Generating and testing strategies for integrating caregivers into formal health care settings
- Promoting the use of technology to support informal cancer caregivers

Patients’ perspectives on the cost of cancer care
The cost of cancer care in the United States totaled about $122 billion in 2013, which represented an estimated 6% of overall personal health care spending of $2.44 trillion, according to data from CMS’s National Health Expenditure Accounts. Even with the adoption of more expensive targeted treatments as standards of care, however, cancer treatment costs rose more slowly (a 5% annual rate) than the overall 6% increase of all personal health care spending in the 1996–2013 period. However, other estimates of health care spending find that outlays for cancer care are matching or outpacing the treatment costs of other disease states. The cost issue is compounded by concurrent increases in the costs of diagnostic imaging. Annual increases in imaging have occurred across all major cancer types.

Financial toxicity in cancer
With both the cost of care and out-of-pocket (OOP) expenses rising, patients—even those with insurance—are increasingly dealing with cost implications as part of their cancer experience. According to some health care experts, OOP expenses might have such an impact on the cancer experience as to warrant a new term: “financial toxicity.” The OOP expenses associated with treatment are akin to physical toxicity, in that costs can diminish quality of life and impede delivery of the highest quality care. In addition, existing data identify both objective financial burden and subjective financial distress as the primary components of financial toxicity.

Among patients with cancer, financial toxicity due to high OOP treatment expenses may reduce quality of life and hamper the delivery of quality care. Patients experiencing high OOP costs have reported that they cut their spending on food and clothing, lowered the frequency with which they take prescribed medications, and avoided scheduled appointments with physicians to save money.
These unintended consequences risk an increase in health disparities, and they appear to run counter to some of health care reform’s key goals. Yousuf Zafar, MD, shared his thoughts on this important topic in an interview found on pages 12-13.

Challenges presented across the age continuum

Cancer touches every age group in a different way, whether it’s physically, mentally, and/or socially.

From a clinical perspective, younger patients may tolerate more-aggressive treatment better than geriatric patients, many of whom have comorbidities that may affect their cancer treatment or lead to more debilitating side effects. Cancer and its treatment lead to emotional and psychosocial aspects, also. These aspects are likely different for patients in their 20s in the midst of dating and career aspirations than they will be for a 60-year-old patient contemplating retirement.

Perhaps surprisingly, much of the foundation of oncology today is supported by early advances in treating pediatric cancer, advances that have set the standard for several key elements of quality care. This includes interdisciplinary team-based care, translational research that brings basic discovery from the laboratory to the clinic and back, and the effort to combine compassion with care all along the care continuum.

Cancer and children (ages 0–14 years)

The treatment of childhood cancer is one of the major success stories in 20th century medicine. This success is exemplified by acute lymphoblastic leukemia, an incurable disease in the 1950s that by the end of the century showed 5-year survival rates approaching 90%. Other childhood cancers also showed marked improvements in outcome in the 20th century, including Wilms tumor, non-Hodgkin lymphoma, Hodgkin lymphoma, and germ-cell tumors. However, substantial continuing challenges remain. In some areas of pediatric cancer, care and treatment progress has been slow, and it is estimated that approximately 1,250 children die of cancer each year.

Children and adolescents with cancer diagnoses face issues similar to those of their adult counterparts, but with important and clinically relevant differences. Research indicates that health care for children with cancer should include psychological services to prevent long-term emotional and behavioral problems. Yet, for children with cancer, even more comprehensive psychosocial programs are needed. These programs should be delivered in an environment that is both age- and developmentally appropriate, and delivered in a time-sensitive fashion.

Research indicates that health care for children with cancer should include psychological services to prevent long-term emotional and behavioral problems.
HELPING PATIENTS MANAGE FINANCIAL CHALLENGES OF CANCER CARE

Yousuf Zafar, MD, MHS, Associate Professor of Medicine and Public Policy at the Duke Cancer Institute and Sanford School of Public Policy, and Director of the Center for Applied Cancer Health Policy, is a medical oncologist with a focus on patients who have gastrointestinal cancers. In addition, Dr. Zafar is a health services researcher and has participated in several studies focusing on access to care, cost of care, and comparative effectiveness of care delivery between health systems.

Dr. Zafar became interested in the topic of financial toxicity in cancer care during the economic downturn when he noticed an increasing number of patients who were having difficulty affording their treatment, as well as the cost of travel, to the treatment center. “We didn’t have a really great understanding of how much patients were paying out of pocket (OOP) for their cancer treatment, and more importantly, the impact that it was having on their lives,” said Dr. Zafar.

According to Dr. Zafar, several factors are driving the financial burden related to cancer care:

- The cost of interventions has been increasing dramatically over the past few decades, including treatments, facility fees, and diagnostics
- Patients are on treatment longer, in part because the treatments are more effective and more tolerable, which adds to the cost burden
- Costs have shifted from payers to patients in the form of higher copays, high-deductible plans, and tiered formularies

In addition, many patients lack a fundamental understanding of health insurance and have the mistaken notion that because they have insurance, their treatment costs are covered. Yet, patients increasingly are sharing a greater burden of treatment costs through coinsurance, copays, and high deductibles. “They don’t expect that until they get the first bills, which can be shocking,” Dr. Zafar said. There is very little awareness or financial literacy related to insurance benefits and OOP costs.

Discussions around the cost of care

Neither patients nor providers raise the topic of treatment costs as frequently as they should, said Dr. Zafar, and both groups have their own reasons for avoiding this discussion. Similar to treatment-related physical toxicities, physicians need to be aware of financial toxicity. For example, unless a physician knows a patient is experiencing chemotherapy-induced nausea, he or she won’t know to adjust the treatment regimen. Dr. Zafar views the cost issue similarly—he needs to know that patients are facing financial problems related to the cost of care, so he can look for resources to help them.

Studies show that about one-third of patients believe asking their provider about the costs of care may result in “lesser quality care,” and other patients are either embarrassed by the topic or don’t believe they should address the costs of care with their physicians, Dr. Zafar said.

Dr. Zafar said providers often avoid cost discussions because they don’t always know how much a particular intervention will cost a specific patient or they sense that bringing up the cost of treatment may be perceived by the patient to be motivated by a societal perspective or reimbursement concern. Financial issues are complicated by a lack of transparency around treatment costs and by the vagaries of insurance coverage for each patient. Another barrier is the time it takes to hold detailed discussions with patients about cost of care, especially when reimbursement of such discussions is questionable.

Dr. Zafar said the urgency of expanding the patient-provider discussions of treatment costs has reached or exceeded the tipping point. Health care-related spend is the leading cause of all personal bankruptcy in the United States, even for patients who have health insurance coverage. Treatment costs also can affect family members of cancer patients who are trying to help pay off these debts.

“I think financial toxicity is an important term in that it frames the idea of financial burden as a side effect of treatment. When it is described as a side effect of treatment, I think we see the urgency around intervening on that side effect.”
An app to address financial toxicity

Dr. Zafar and several of his colleagues are developing an app for cancer patients that offers tips for initiating discussions with physicians about treatment costs. The beta version of the app uses a framework built around palliative care and end-of-life discussions. In pilot testing at the Duke Cancer Institute, patients found it to be very usable and effective, and the next step is to test the app on a broader scale, he said.

The next version is expected to have four distinct features:
1. A financial distress screening tool
2. A financial educational resource (with information about the Affordable Care Act and other aspects of health insurance, including definitions of key terms)
3. An interactive communication coaching tool
4. Real-time connections to patient-assistance programs for various cancer treatments

Helping patients become actively involved

Dr. Zafar said it is important for patients to understand that there are few resources available to help them get out of debt once it is incurred. Available resources are designed to prevent patients from accruing overwhelming debt. He believes that one opportunity to ease the financial burden of cancer care rests with helping patients become more involved with finding assistance programs “right at the start of treatment.”

Financial navigators also can play a larger role than they currently play, but patients often don’t engage with a navigator until after they’ve already incurred large medical debt.

Dr. Zafar said he believes financial counseling should be part of the service menu providers offer to new patients, which already is occurring in some community medical practices. The counseling services should continue across the care continuum through survivorship. However, he noted, there has not been enough research on the process to produce data demonstrating its effectiveness. He has done studies that have shown that patients receiving cancer treatment and those who are into survivorship are “still experiencing financial strain as a result of their treatment.”

Best practices for managing the cost of care

Dr. Zafar recommended ways all stakeholders involved in cancer care—patients, payers, and providers—can appropriately address the issues that arise from the cost of treatment. He suggested patients contact their insurance company in advance to understand what treatments are covered and what are not covered, “question early and often” during their treatment regimen to help determine their OOP costs for care, talk to a financial counselor, and discuss their financial burden with their providers.

Health plans should provide better tools to patients for understanding key benefit terms, such as deductibles and OOP costs. The Web-based version of these tools must be updated in real time, Dr. Zafar said.

Providers should “check in” frequently with patients about prescription drug coverage and whether the treatment regimen is affordable. “Patients need to know which resources are available, and more importantly, who to go to for help. I may not know how much any particular regimen is going to cost, but I do know who has that information and who to go to for help,” Dr. Zafar said.

Ultimately, Dr. Zafar suggested there should be a greater focus on health-policy interventions, which require a longer timeframe to consider and implement, as one possible solution to the financial issues of cancer care. Insurance design can be changed to allow for more affordability, he added. This could include broader acceptance of value-based, or even performance-based, insurance.
Cancer among adolescents and young adults

Cancer is the leading disease-related cause of death in the adolescent and young adult (AYA) age group. Each year, nearly 70,000 AYAs between the ages of 15 and 39 are diagnosed with cancer, approximately six times more than children under age 15. The prevalence of types of cancer varies by age (Figure 3). In addition, AYAs face different challenges than other age groups in having their cancers diagnosed, treated, and monitored. Monitoring draws substantial interest because of the apparent lack of improvement in outcomes previously documented for this age group as compared with outcomes for the younger and older patient populations.

In a 2014 review of cancer registries, researchers found that, in general, data suggest that AYAs are faring well in terms of cancer survival as compared with the younger and older population groups. However, data also suggest that outcomes are not the same across cancer types for all age groups. AYA survival was found to be worse for female breast cancer, acute lymphoid leukemia, and acute myeloid leukemia as compared with younger and older survivors.

Another factor that sets this age group apart is that AYAs are at a unique stage in their emotional, cognitive, and social development, and often encounter significant life disruptions during their cancer journey. For younger AYAs, cancer can interfere with their efforts to establish independence from their parents, while older AYAs may have their careers or search for a life partner disrupted. As more young people survive their cancer, future fertility issues represent a needed area of care. A 2012 LIVESTRONG survey of 1,338 AYAs found that approximately one-fourth of AYAs took steps to preserve their fertility before their cancer treatment began. Those who did not gave a variety of reasons, the most concerning of which was a lack of information about risks of infertility or fertility options (Figure 4).

Cancer and older adults

The incidence of cancer increases dramatically in the final decades of life, as indicated by data that show roughly 60% of newly diagnosed malignancies and 70% of cancer deaths

---

**Figure 3: Common types of cancers affecting adolescents and young adults**

<table>
<thead>
<tr>
<th>Ages</th>
<th>Number of observed cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>15–19</td>
<td>0 30,000 20,000 15,000 10,000 5,000 0</td>
</tr>
<tr>
<td>20–24</td>
<td>0 30,000 20,000 15,000 10,000 5,000 0</td>
</tr>
<tr>
<td>25–29</td>
<td>0 30,000 20,000 15,000 10,000 5,000 0</td>
</tr>
<tr>
<td>30–34</td>
<td>0 30,000 20,000 15,000 10,000 5,000 0</td>
</tr>
<tr>
<td>35–39</td>
<td>0 30,000 20,000 15,000 10,000 5,000 0</td>
</tr>
</tbody>
</table>

- Leukemia and lymphoma
- Central nervous system
- Breast
- Soft tissue and Kaposi sarcoma
- Germ cell
- Thyroid
- Melanoma of the skin
- Malignant bone tumors
- Cervix and uterus
- Other

*Includes testicular cancer. **Includes breast, cervix, colon, and other less prevalent cancers.
take place in people who are 65 years or older. The data also show the age-adjusted cancer incidence rate is 10-fold greater, and the age-adjusted cancer mortality rate is 16-fold greater in those 65 years of age or older, compared with these rates in people younger than 65 years.\textsuperscript{41}

Traditionally, the study of cancer has focused on younger, healthier patients, which has resulted in a dearth of high-quality data to adequately guide care for older patients. However, efforts are under way to gain greater knowledge of the relationship between aging and cancer, as well as an increase in evidence-based research to guide the care of older adults with cancer.\textsuperscript{42} It is critical in the treatment planning stage to determine how the patient’s status may be improved and to define what remedial measures might be instituted.\textsuperscript{41}

\begin{table}[h]
\centering
\begin{tabular}{|l|c|c|}
\hline
\textbf{Reasons} & \textbf{Percentage of patients} \\
\hline
Not interested in having more children & Male: 42\%  & Female: 39\%  \\
\hline
Not at risk for infertility & Male: 19\%  & Female: 12\%  \\
\hline
Not enough time & Male: 18\%  & Female: 25\%  \\
\hline
No information about options for fertility preservation before treatment began & Male: 14\%  & Female: 21\%  \\
\hline
Too expensive & Male: 14\%  & Female: 13\%  \\
\hline
No information about risks to fertility due to cancer and its treatment & Male: 12\%  & Female: 15\%  \\
\hline
\end{tabular}
\caption{Reasons adolescents and young adults did not employ fertility preservation\textsuperscript{40}}
\end{table}

\textbf{FACTORS IMPORTANT TO OLDER ADULTS WITH CANCER}\textsuperscript{41}

\begin{table}[h]
\centering
\begin{tabular}{|l|l|}
\hline
\textbf{Factor} & Description \\
\hline
\textbf{Functional status} & Older adults need to be screened for the ability to perform activities of daily living, level of mobility, risk for falls, and visual and auditory acuity \hline
\textbf{Cognitive function} & Older adults with cancer and impaired cognition are at risk for noncompliance and nonadherence to therapeutic regimens, as well as for delirium and early death \hline
\textbf{Comorbidities} & Many older patients have various disorders and related treatments that could potentially affect tumor growth, therapeutic efficacy, and treatment tolerance \hline
\textbf{Geriatric syndromes} & Syndromes, such as dementia, delirium, depression, distress, osteoporosis, falls, fatigue, frailty, and urinary incontinence, can adversely affect disease progression and therapeutic tolerance \hline
\textbf{Polypharmacy} & An increased risk of drug interactions and adverse drug effects accompany the use of increased and excessive numbers of prescribed and nonprescribed medications \hline
\textbf{Psychological status} & Emotional disorders in the elderly, particularly depression, may interfere with acceptance or adherence to therapeutic strategies, management of side effects, and personal care \hline
\textbf{Social support} & Social isolation and the perception of loneliness increase the risk for mortality, especially in the elderly \hline
\textbf{Nutritional status} & Nutritional deficiency and malnutrition may be particularly problematic in older adults \hline
\end{tabular}
\caption{Factors important to older adults with cancer}\textsuperscript{41}
\end{table}
Summary

The Patient Voice Across the Cancer Care Continuum: Survivorship, End of Life, and Other Cancer Care Issues highlights the importance of the patient voice with regard to patient survivorship, end-of-life care, and other key cancer care issues, such as:

- Patient perspectives on survivorship, including the key components of a survivorship care program, ways to support patients after active treatment, and the importance of a care plan
- The benefits of providing biomedical, psychosocial, and spiritual support to those facing the end of life
- The important role caregivers play across the cancer care continuum
- Patient perspectives on the cost of cancer care and the effect of financial toxicity on their quality of life
- The challenges of treating cancer across the age continuum

Insights into the patient voice through other phases of cancer care are further explored in two companion reports in this series: The Patient Voice Across the Cancer Care Continuum: Screening, Diagnosis, and Prehabilitation and The Patient Voice Across the Cancer Care Continuum: Treatment.

Appendix/Resources

Genentech Resources

Below is a sampling of initiatives and resources sponsored or supported by Genentech to assist patients, family caregivers, clinicians and other stakeholders throughout the cancer care continuum.


Each interactive session in the Care Management Workshop Series provides an opportunity for care managers to learn and discuss key patient issues and challenges. Experts lead the 1- to 2-hour workshops, which can be attended live or via webcast. In oncology, the following workshop topics are available: Foundations of Oncology, Palliative Care, Psychosocial Issues in Cancer Care, and Cancer Survivorship. The objectives of the care management workshops are to equip care managers with the skills to better guide and advocate for patients during their treatment journey and to improve the efficiency and quality of care for patients living with chronic and advanced illness.

Journey Forward (http://www.journeyforward.org/)

Journey Forward was developed in response to the 2005 Institute of Medicine report From Cancer Patient to Cancer Survivor: Lost in Transition, which revealed poor cancer care coordination and a deep lack of awareness about survivorship care needs among cancer survivors. A unique collaboration involving Genentech began in 2008 to develop tools for oncology professionals and primary care physicians, as well as cancer survivors, to address needs for coordinated follow-up care once active treatment comes to an end. These include free survivorship care plan builder software for clinicians, a medical history builder resource for survivors, a directory of survivorship resources and a searchable online library of survivorship articles available from the Web site. Included in the patient tools are two mobile phone applications (apps)—the Self-Care app and the My Care Plan app.

Love Your Colon (http://loveyourcolon.org/)

Love Your Colon, founded in 2007, is an initiative designed to increase awareness of colorectal cancer and the importance of screening. The goal is to increase screening rates and decrease the number of colorectal cancer-related deaths. Through customizable resources on the Web site, communities at-large, health care providers, employers, and payers can educate and encourage their citizens, patients, employees, and members to take action against colorectal cancer.
**General Resources**

Below is a sampling of initiatives and resources sponsored by public and private organizations to support patients, family caregivers, clinicians and other stakeholders throughout the cancer care continuum. Genentech does not endorse these organizations nor the views they express or the products/services they offer. These listed organizations below are provided solely for information purposes. Genentech does not control or guarantee the accuracy, relevance, timeliness or completeness of information provided by these organizations.

**Cancer and Careers**
(http://www.cancerandcareers.org/en)

Cancer and Careers helps nearly 300,000 people each year — online, in print, and in person — by providing valuable information and resources via expert advice, interactive tools, and educational events.

**CancerCare®**
(http://www.cancercare.org/)

Founded in 1944, CancerCare is the leading national organization providing free, professional support services and information to help people manage the emotional, practical, and financial challenges of cancer.

**Cancer Experience Registry**
(https://www.cancerexperienceregistry.org/)

The Cancer Experience Registry is a grassroots effort to engage participants who have been impacted by cancer to answer questions about their social and emotional experiences and needs throughout their cancer journey. It is a research project driven by people living with cancer and their caregivers.

**Cancer Financial Assistance Coalition (CFAC)**
(www.cancerfac.org)

CFAC is a coalition of financial assistance organizations joining forces to help cancer patients experience better health and well-being by limiting financial challenges.

**Cancer.Net**
(http://www.cancer.net/)

Cancer.Net provides timely, comprehensive, oncologist-approved information from the American Society of Clinical Oncology (ASCO), with support from the Conquer Cancer Foundation. Cancer.Net brings the expertise and resources of ASCO to people living with cancer and those who care for and about them to help patients and families make informed health care decisions.

**Cancer Support Community (CSC)**
(http://www.cancersupportcommunity.org/)

As the largest professionally led, nonprofit network of cancer support worldwide, the CSC is dedicated to ensuring that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community. CSC achieves its mission through three areas: direct service delivery, research, and advocacy. The organization includes an international network of affiliates that offer the highest quality social and emotional support for people impacted by cancer, as well as a community of support available online and over the phone. The Research and Training Institute conducts cutting-edge psychosocial, behavioral, and survivorship research. CSC furthers its focus on patient advocacy through its Cancer Policy Institute, informing public policy in Washington, DC, and across the nation.

**Coping® With Cancer**
(http://copingmag.com/cwc/index.php/about/about_coping/about_us/)

The Coping with Cancer Web site is a complete online experience that educates and inspires. It is presented in a warm and friendly, easy-to-use format, and provides information by specific cancer type, general knowledge about living with cancer, and wellness and inspirational topics.

**Global Resource for Advancing Cancer Education (GRACE)**
(cancergrace.org/)

GRACE provides expert-mediated information on current and emerging cancer management options in order to empower patients, caregivers, and health care professionals to become direct partners in cancer care.

**Critical Mass: The Young Adult Cancer Alliance**
(criticalmass.org)

Critical Mass is a community-powered advocacy organization whose mission is to transform the care and treatment of young adults with cancer.

**Informed Medical Decisions Foundation**
(http://www.informedmedicaldecisions.org/)

The Informed Medical Decisions Foundation, now a division of Healthwise, has been working to advance evidence-based, shared decision making since 1989. They believe the only way to ensure that high-quality health care decisions are being made is for fully informed patients to participate in a shared decision-making process with their clinician. Through research and advocacy efforts, the foundation is dedicated to helping people make better health decisions.
MetaCancer Foundation (metacancer.org)

The MetaCancer Foundation provides resources and support for metastatic cancer survivors and their caregivers. MetaCancer encourages dialogue among those with very different types of metastatic cancer (breast, prostate, colorectal, ovarian, bladder/urinary, skin, lung, testicular, among others), even though respective treatment protocols and medical issues may seem to have little in common with each other. The common bonds are the psychological and emotional realities faced by anyone living with metastatic cancer. MetaCancer provides resources for everyday living, opportunities for creative reflection, and possibilities for you to “go meta”: to live beyond your diagnosis right now with strength, grace, and peace.

Mobile Resources Selected by the Memorial Sloan Kettering Library: Patients & Caregivers (http://libguides.mskcc.org/c.php?g=245150&p=1632654)

Mobile resources are categorized as follows: Health-U.S. Government, About Cancer, Quit Smoking, Medication-Related Resources, Diet and Fitness, Signs and Symptoms, Emergencies and First Aid, Resources to Feed the Mind, Local Amenities and Other Useful Health sites and apps.

My Cancer Circle (http://mycancercircle.lotsahelpinghands.com/)

My Cancer Circle, powered by Lotsa Helping Hands, is a simple online tool that helps organize the community of people who want to help caregivers of patients with cancer. It coordinates their efforts to more efficiently support the caregiver and the loved one facing cancer. My Cancer Circle coordinates volunteer activities, including meals, transportation to medical appointments and other tasks; provides a private space where community members can offer words of support and encouragement and where caregivers can post updates and information about their loved one; and schedules offers to give caregivers a break or to do something special for them.

National Cancer Institute (NCI) (http://www.cancer.gov)

NCI offers free, credible, current, comprehensive information about cancer prevention and screening, diagnosis and treatment, research across the cancer spectrum, clinical trials, and news and links to other NCI Web sites. The Web site contains excellent resources for both patients and caregivers.

National Cancer Legal Services Network (NCLSN) (www.NCLSN.org)

NCLSN promotes access to health care and seeks to increase the availability of legal services for people living with cancer, their families, and caregivers. Through direct work, educational efforts and advocacy, this multidisciplinary coalition helps to alleviate the legal and economic consequences of cancer so that those affected may focus on their medical care and quality of life. The NCLSN supports the efforts of individuals and organizations focused on meeting the legal needs of the cancer-affected community. It augments the voice of disparate services, creates a forum for established and nascent legal advocacy groups, and facilitates the development of similar programs.

National Coalition for Cancer Survivorship (NCCS) (http://www.canceradvocacy.org/)

NCCS’ mission is to advocate for quality cancer care for all people touched by cancer. Founded by and for cancer survivors, NCCS created the widely accepted definition of survivorship and defines someone as a cancer survivor from the time of diagnosis and for the balance of life.

National Colorectal Cancer Roundtable (NCCRT) (http://nccrt.org/)

NCCRT, established by the American Cancer Society and the Centers for Disease Control and Prevention in 1997, is a national coalition of public, private, and voluntary organizations and invited individuals dedicated to reducing the incidence of and mortality from colorectal cancer in the United States, through coordinated leadership, strategic planning, and advocacy. The NCCRT campaign “80% by 2018” aims to reach 80% screening rates for colorectal cancer by 2018, and has over 1,000 organizations pledging support across the United States.

NCCN Patient and Caregiver Resources (nccn.org/patients)

NCCN Guidelines for Patients® are translations of the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) and are designed to help patients with cancer talk with their physicians about the best treatment options for their disease. This Web site provides state-of-the-art cancer treatment information in easy-to-understand language.
PatientsLikeMe®
(https://www.patientslikeme.com/)
Members of PatientsLikeMe contribute directly to research through data sharing to advance understanding of the disease in a way that can accelerate discovery and improve care. Patients have the opportunity to share both personal stories and health data about their conditions to help put their disease experiences in context and find answers to the questions they have. In addition, PatientsLikeMe’s Open Research Exchange (https://www.openresearchexchange.com/) has created an open platform for developing, validating, and sharing health-outcome measures that better reflect patients’ experiences with a disease, and assess health and quality of life in ways that matter to patients.

Preparatory Education About Clinical Trials (PRE-ACT)
(http://www.cancer.net/navigating-cancer-care/how-cancer-treated/clinical-trials/pre-act)
This educational program is designed to provide general information about clinical trials. PRE-ACT was developed with support from the National Cancer Institute to help cancer patients better understand what clinical trials are and how they work.

Reimagine
(https://reimagine.me/)
Reimagine is a powerful collection of tools that are designed to help everyone in the cancer community feel better, all based on The Seven Pillars of Personal Strength™. The program consists of 10 self-paced online modules with more than 100 activities, videos, and live sessions. The Core Program will help patients, survivors, friends, and family learn a proven set of skills for navigating the challenges of cancer and life. It is an essential component of any Survivorship Care Plan and a powerful tool for people who score a four or above on the Distress Thermometer.

Triage Cancer
(http://triagecancer.org/)
Triage Cancer works to address cancer-related health disparities through the delivery of cancer survivorship education, particularly information related to accessing care. Information is tailored to specific cancer-community audiences, including childhood cancer survivors and their parents, adolescents and young adults, seniors, newly diagnosed patients, individuals who have completed treatment, individuals with advanced disease, caregivers, advocates, and health care professionals.

US Preventive Services Task Force (USPSTF)
(http://www.uspreventiveservicestaskforce.org)
USPSTF develops recommendations for preventive services, such as screening tests, counseling services, and preventive medications, based on a review of high-quality scientific evidence.

Watson Health Initiative
IBM and the American Cancer Society are launching a new partnership that will combine the power of Big Blue’s cognitive computing platform, Watson, with the wealth of cancer research and patient support services provided by the nonprofit organization. The two organizations will combine forces to create a service that will provide cancer patients, survivors, and caregivers with personalized access to vetted cancer resources.

WhatNext
(https://www.whatnext.com/)
The American Cancer Society has a new online tool called WhatNext that has unique, patent-pending technology to connect people based on their specific diagnosis and medical experiences. On WhatNext, people can easily access relevant firsthand experiences posted by others in similar circumstances, share their experiences, and get answers to their questions. Rare Patient Voice, LLC, has a partnership with WhatNext, which makes available 32,000 cancer patients and caregivers for qualitative and quantitative research.
References:


Issues in Focus:
The Patient Voice Across the Cancer Care Continuum

A series of informational white papers provided by Genentech, South San Francisco, CA

Produced by Emron, Wayne, NJ
www.emron.com