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Cancer Quality Alliance: Blueprint for a Better Cancer Care System

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ABSTRACT The Cancer Quality Alliance (CQA), a national alliance advocating for improvements in the quality of cancer care in America, presents a set of 5 case studies that depict a vision of quality cancer care and a “Blueprint” for actions to realize this vision. The CQA Blueprint case studies feature patients with soft tissue sarcoma, breast cancer, rectal cancer, and Hodgkin disease and focus on key phases in the cancer care trajectory: detection, diagnosis, treatment, post-treatment/survivorship, and end of life. Each case study begins with a patient summary, follows with a worst- and a best-case scenario, and concludes with a discussion section identifying “what went right” in the best case and “what went wrong” in the worst case. Steps to be taken by key stakeholders, for example, health care providers, insurers/payers, policy makers, and patients and families, are then outlined. By juxtaposing a worst- and best-case scenario, the cancer care case studies elucidate the origins of complex health care problems and clarify the actions needed to overcome them. The CQA will make the case studies available for use as teaching tools to give health care providers and patients themselves descriptions of how the health care system should work to achieve the ultimate benefit for an individual living with, through, and beyond a diagnosis of cancer. The CQA adopted the definition of quality health care of the Institute of Medicine, and the analysis of care provided in the discussion section of each case study is framed using 6 quality improvement aims identified in the Institute of

Medicine’s report, *Crossing the Quality Chasm: A New Health System for the 21st Century*. Health care quality may be judged according to its safety, effectiveness, patient-centeredness, timeliness, efficiency, and equity. (*CA Cancer J Clin* 2008;58:266–292.) © American Cancer Society, Inc., 2008.

INTRODUCTION

Everyone facing the threat of cancer expects to receive care that is of high quality, well coordinated, and delivered with compassion. Health care providers uniformly attempt to meet their patients’ expectations and deliver such quality care; however, shortcomings of the system in which cancer care is delivered often impede their best efforts. Both patients and providers are often left frustrated and unable to achieve optimal care and outcomes.

While many initiatives are underway that together promise to incrementally improve systems of care, a clear picture of what high-quality cancer care would look like is missing. The Cancer Quality Alliance (CQA), a diverse group of individuals representing organizations committed to working toward improved systems of care, is attempting to create a vision or “Blueprint” of quality care (<http://www.cancerqualityalliance.org>). Members of the CQA include cancer care providers, patient advocacy groups, certifying and accrediting organizations, public and private payers, federal agencies, foundations, and other national organizations involved in improving the quality of cancer care. By encouraging the sharing and implementation of measures, tools, and practical programs to improve quality, the CQA seeks to become a national voice for the quality of cancer care.

Disclosure: Dr. Rose is Chief Technology Officer for Vantage Oncology, Inc. No other potential conflict of interest relevant to this article was reported.

The CQA Blueprint Workgroup has developed a set of 5 cancer care case studies that present examples of systems failures that occur in real life, interventions to overcome these failures, and action steps to be taken to achieve best-case care. Together, the scenarios represent a “Blueprint” for action. The Blueprint case studies convey a vision of the best cancer care imaginable and, at the same time, achievable. The CQA will make the case studies available for use as teaching tools to give health care providers and patients descriptions of how the health care system should work to achieve the ultimate benefit for an individual living with, through, and beyond a diagnosis of cancer.

The 5 case studies feature patients with soft tissue sarcoma, breast cancer, rectal cancer, and Hodgkin disease and focus on key phases in the cancer care trajectory: detection, diagnosis, treatment, post-treatment/survivorship, and end of life. Each case study begins with a patient summary, follows with a worst- and a best-case scenario, and concludes with a discussion section identifying “what went right” in the best case and “what went wrong” in the worst case. Steps to be taken by various stakeholders, for example, health care providers, insurers/payers, policy makers, and patients and families, are then outlined. By juxtaposing a worst- and best-case scenario, the Blueprint case studies elucidate the origins of complex health care problems and clarify the actions needed to overcome them.

In developing the cancer care case studies, the CQA Blueprint Workgroup adopted the definition of quality health care promulgated by the Institute of Medicine (IOM).^{1,2}

Health care can be judged as good to the extent that it increases the likelihood of desired health outcomes and is consistent with current professional knowledge. In practical terms, poor quality can mean: overuse (eg, unnecessary tests, medication, and procedures, with associated risks and side effects); underuse (eg, not receiving a lifesaving surgical procedure); or misuse (eg, medicines that should not be given together, poor surgical technique).

Quality care means providing patients with appropriate services in a technically competent manner, with good communication, shared decision making, and cultural sensitivity.

Identifying ways to overcome the health care system’s shortcomings to achieve quality cancer care has been the focus of reports issued by the IOM.³⁻⁷ Available evidence on the quality of cancer care indicates that many individuals cared for in a variety of settings experience difficulties with the health care system. These include delays in detection; misdiagnosis and/or an incomplete diagnosis; cancer treatment that differs from current and accepted protocols or treatment guidelines; little or no counseling regarding clinical trial enrollment options; lack of attention to palliative care and/or symptom management; limited monitoring of late- and/or long-term post-treatment side effects; and inadequate and, in many cases, inappropriate end-of-life care.

Among the recommendations made to address these deficiencies in quality is to have systems of care: use evidence-based guidelines, measure and monitor the quality of care, and ensure key elements of quality care for each individual with cancer (eg, care planning, coordinated care, access to clinical trials, psychosocial support services, and compassionate care). Efforts are underway to implement these recommendations and improve cancer care. These efforts include the National Quality Forum’s identification of a core set of measures of quality cancer care, the American Society of Clinical Oncology (ASCO)’s Quality Oncology Practice Initiative to monitor care within oncology practices, The National Comprehensive Cancer Network (NCCN)’s creation of evidence-based clinical practice guidelines, the American College of Surgeons (ACoS) Commission on Cancer’s standard setting for cancer care programs, the Oncology Nursing Society’s Putting Evidence into Practice (PEP) initiative, the National Cancer Institute’s support of research to elucidate factors limiting the delivery of quality care, the Medicare Program’s attempts to align financial incentives with quality initiatives, and numerous consumer organization efforts to inform and assist patients as they navigate the complex cancer care system. The CQA Blueprint Workgroup’s cancer care case studies show how these and other quality-of-care initiatives could transform the health care system, allowing for marked improvements in cancer care outcomes. Well recognized is the need to vary implementation of these efforts by locality and by system of care

with, for example, different mechanisms needed in rural versus urban areas or for particularly high-risk or underserved populations.

The analysis of care provided in the discussion section of each case study is framed using 6 quality improvement aims identified in IOM's report, *Crossing the Quality Chasm: A New Health System for the 21st Century* (Table 1). The aims are based on the philosophy that "the ultimate test of the quality of a health care system is whether it helps the people it intends to help." This simple tenet also served as a basis for the work of the Blueprint Workgroup of the CQA.

The Blueprint Workgroup, in drafting the case studies, adopted the National Coalition for Cancer Survivorship (NCCS) definition of *survivorship*, which is used to describe a process that begins at the time of diagnosis and continues for the rest of one's life. NCCS identifies an individual diagnosed with cancer, as well as his or her extended family and caregivers, as *survivors*. The desirable outcome for survivors is appropriate care before, during, and after treatment, including care at the end of life, without regard to the length of time from detection to death. The Blueprint case studies highlight what cancer care could be—a description of an optimal "survivor's journey."

The case studies are intended to be an educational tool for a broad audience, including all health care providers involved in cancer care,

educators of health professionals, patients, and the general public. In an effort to make the case studies comprehensible to a wide audience, the CQA Blueprint Workgroup has described care in simple terms and minimized the use of medical jargon and technical language.

The CQA Blueprint Workgroup began its work in October 2006 and was initially led by Christopher Desch, MD, and Ellen Stovall in collaboration with Patricia Ganz, MD, and the membership of the CQA. In March 2007, Christopher Rose, MD, assumed leadership of the Workgroup with support from ASCO and NCCS staff and consultants. The Blueprint case studies were developed by Workgroup members following deliberations at CQA meetings and have benefited greatly from reviews and suggestions of interested CQA members.

The names of all patients and providers are fictitious, and the clinical recommendations made within the case studies are not meant to supplant the judgment of oncology providers in the provision of clinical care to any particular individual patient with cancer. Further, these cases represent a vision of ideal care, not a reflection on the current standard of care.

A version of this document has been adapted for health policy makers, advocates, and patients. This longer document, which includes a glossary of medical terms, is available on the CQA Web site (www.cancerqualityalliance.org).

TABLE 1 Six Aims for a New Health System for the 21st Century⁸

1. *Safe*: avoiding injuries to patients from the care that is intended to help them.
2. *Effective*: providing services based on scientific knowledge to all who could benefit and refraining from providing services to those not likely to benefit.
3. *Patient-centered*: providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.
4. *Timely*: reducing waits and sometimes harmful delays for both those who receive and those who give care.
5. *Efficient*: avoiding waste, including waste of equipment, supplies, ideas, and energy.
6. *Equitable*: providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status.

A health care system that achieves major gains in these 6 areas would be far better at meeting patient needs. Patients would experience care that is safer, more reliable, more responsive to their needs, more integrated, and more available, and they could count on receiving the full array of preventive, acute, and chronic services that are likely to prove beneficial. Clinicians and other health workers also would benefit through their increased satisfaction at being better able to do their jobs and thereby bring improved health, greater longevity, less pain and suffering, and increased personal productivity to those who receive their care.

Redesigning the health care delivery system to achieve these aims will require changing the structures and processes of the environment in which health professionals and organizations function, especially in 4 areas: applying evidence to health care delivery, using information technology, aligning payment policies with quality improvement, and preparing the workforce.

CASE ONE: SOFT TISSUE SARCOMA CARE

The Patient

Jake Fenwick consulted his primary care physician, Dr. Philip Harding, when a fist-sized lump he felt in his right thigh did not go away. Dr. Harding had taken care of the 47-year-old for several years and knew him to have no serious health problems. Dr. Harding was concerned about the lump and ordered a computed tomographic (CT) scan. A solid mass extending to the bone was visible on the scan. Dr. Harding immediately scheduled a visit to discuss these findings with Mr. Fenwick.

Mr. Fenwick works as a surveyor in a small Midwestern community. He is married with 2 children, one of whom was leaving for college in the fall.

A Worst-case Scenario

Dr. Harding informs Mr. Fenwick that he probably has cancer but that the CT scan does not indicate that the cancer has spread to other organs. Dr. Harding reassures Mr. Fenwick and suggests that Dr. Frame, the general surgeon practicing in the office next door, can take care of the problem. An appointment with Dr. Frame is scheduled for several weeks later. At the initial appointment, Dr. Frame recommends that the tumor be surgically removed, and Mr. Fenwick proceeds to schedule the operation.

Dr. Frame surgically removes a firm, white tumor but has trouble freeing the tumor from nearby blood vessels and bone. The pathologist calls Dr. Frame a few days later to inform him that the tumor is an aggressive soft tissue sarcoma. Several of the edges (margins) of the removed tissue were found to include cancer cells, including the portion of the tissue near the bone. With these findings, Dr. Frame refers Mr. Fenwick to a radiation therapy facility 15 miles away. Mr. Fenwick's radiotherapy treatment includes extra doses of radiation to the area next to the bone where cancer cells likely remained. Mr. Fenwick's physicians do not suggest that he consult any other specialists.

Six months later, Mr. Fenwick returns to his primary care doctor after finding a lump near the surgical scar and within the area treated with

radiation. New imaging studies reveal that the tumor has grown and has wrapped around one of the major arteries of his leg. The surgeon, Dr. Frame, is consulted again. He explains that amputation near the hip is the only treatment option. Frightened, and at the urging of his wife and brother, Mr. Fenwick makes an appointment for a second opinion at a comprehensive cancer center several hours drive from his home. The cancer center specialists express regret that Mr. Fenwick had not been referred to a medical oncologist either initially or when it was discovered that the first surgery had not succeeded in completely removing the tumor. They conclude that the radiation therapy he had received was appropriate but that the result may have been better if the radiotherapy had been planned in consultation with a medical oncologist. The bottom line was the same, though—at this point, amputation is the only treatment option.

Mr. Fenwick agrees to the amputation. He suspects that he will die regardless of the treatment. He cannot bring himself to ask about his prognosis, and his doctors do not discuss his chance of dying. He fears that if he survives, he will be disabled and unable to continue working. The prospect of not being able to actively care for and financially support his family is devastating. Of particular concern is the very real possibility that he will be unable to support his daughter's college costs. On learning how Mr. Fenwick's cancer care could have been managed differently, the family is confused and very angry. After the amputation, Mr. Fenwick does not receive adequate rehabilitation services and cannot resume his work as a surveyor. Mr. Fenwick suffers severe depression, is determined to be totally disabled, and is placed on long-term disability. The family finds a lawyer and files a malpractice suit against all the doctors and the hospital that provided early care.

A Best-case Scenario

Following his review of the CT scan, Dr. Harding refers Mr. Fenwick to Dr. Lerman, a local surgeon actively involved in the quality-of-care initiatives of the ACoS Commission on Cancer. Dr. Lerman suspects that the mass is a soft tissue sarcoma. She last treated a patient with

such a tumor a few years ago and goes online to review current diagnostic and treatment options suggested by NCCN clinical practice guidelines. Dr. Lerman performs a core biopsy and learns from the pathologist that Mr. Fenwick has a high-grade sarcoma. Mr. Fenwick is immediately called into her office to discuss his diagnosis and treatment options. Mr. Fenwick is encouraged to bring his wife to the appointment.

Dr. Lerman informs Mr. and Mrs. Fenwick of the diagnosis, noting that sarcoma is relatively rare, with fewer than 10,000 cases in the United States each year. She acknowledges that better survival and quality of life are achieved at comprehensive cancer centers and with providers who have extensive experience with sarcoma. Dr. Lerman refers Mr. Fenwick to a cancer center that manages a high volume of sarcoma cases. Mr. Fenwick's health plan has compiled statistics on outcomes of care for such rare cancers and has a policy to pay for services provided at designated "centers of excellence." Dr. Lerman's office administrator informs the Fenwicks that most of the costs of care (and some overnight accommodations for family members) are covered if he goes to the facility that Dr. Lerman has referred him to, a comprehensive cancer center 250 miles away.

Nurse White introduces the Fenwicks to a social worker who provides the Fenwicks with the list of hotels near the cancer center. The social worker advises the Fenwicks to contact their insurance company to confirm coverage of costs related to treatment away from home. Nurse White talks to them about what to expect at the comprehensive cancer center and provides the name of the nurse coordinator they will meet there.

Recognizing that the Fenwicks are overwhelmed with the information about the diagnosis, prognosis, and treatment plans, Dr. Lerman provides the Fenwicks with a written summary of their consultation as they leave the office (which is also provided to Dr. Harding electronically). She directs the Fenwicks to a Web-based patient information site on his specific kind of cancer and discusses the availability of psychosocial support services in their community. Nurse White uses this time to answer questions, explain medical terms, and respond to other concerns the Fenwicks have.

The Fenwicks travel to the comprehensive cancer center the following week. Olivia Stone, a volunteer, meets them at the front desk, helps them through the registration process, and then directs Mr. Fenwick to the surgical oncologist's office 2 blocks away. Mr. Fenwick gives the surgical oncologist, Dr. Alvarez, the DVD his primary care doctor sent with him containing his pathology reports, CT scan results, x-rays, laboratory results, and clinical notes. Nurse Brown, the coordinator and patient navigator, establishes contact with Mr. and Mrs. Fenwick, and she provides an outline of what they can expect to occur at their visit at the cancer center.

Dr. Alvarez reviews the history, clinic notes, pathology reports, laboratory reports, and CT scan results. He concludes that the sarcoma is located too close to the bone to assure a safe margin with an immediate operation. He arranges for Mr. Fenwick to see the radiation oncologist, who explains the benefits and risks of preoperative chemotherapy and radiation and discusses their institution's experience in using this combined treatment-modality approach to decrease the likelihood of amputation. Mr. Fenwick's type of sarcoma is currently being investigated in a Phase II trial using a targeted radiotherapy approach. Although unproven, this is a promising treatment option for him. All usual costs for the experimental treatment are covered by his insurance.

Mr. Fenwick's insurance plan pays for an overnight stay, allowing him to see a medical oncologist the next day and learn more about the clinical trial. The medical oncologist accesses the medical records and preliminary treatment plan electronically, adds some notes, and prints out a revised treatment plan. This detailed plan describes the doses, duration of treatment, purpose (curative/limb-sparing), expected side effects, and how they might be managed if they occur. The plan also provides details on the aim of the research study, which is to judge the effectiveness of chemotherapy in combination with carefully monitored doses of radiation in shrinking the tumor to permit complete surgical removal of the tumor. As the nurse coordinator, Nurse Brown discusses what a clinical trial is and what research question is being asked in this trial. She reviews all potential benefits and side effects with the Fenwicks. She informs the Fenwicks about

the follow-up procedures and visits to the comprehensive cancer facility that the trial would require. The physician and nurse help the patient make an informed choice.

The patient navigator anticipates that the planned multimodal treatment will take Mr. Fenwick out of commission for several weeks and arranges consultations with social work and financial counselors to help estimate expenses and coordinate a payment plan for the family. Applications for short-term disability are filed before the onset of treatment. Because the health plan recommended the comprehensive cancer center based on its sarcoma treatment volume and outcomes, the social worker offers to help Mrs. Fenwick find (and pay for) a small apartment for the 4-night stay required each week for the 7 weeks of preoperative therapy.

Recognizing the hardships of receiving care so far from home, the social worker informs the family of an alternative plan. Instead of making the weekly lengthy trips to the comprehensive cancer center, Mr. Fenwick could opt for the center's "Shared Management Program" in which he would receive care from medical oncology and radiation oncology practices in his own community. This relatively new care-delivery arrangement is available following the cancer center's affiliation with a network of community-based practices. The network providers agreed to adopt the center's standard protocols and guidelines for care and, in addition, to participate in center-led research and quality-control programs. The Fenwicks are relieved to hear that they will be able to receive high-quality care for Mr. Fenwick's rare tumor in their own community and gratefully enroll in the Shared Management Program.

Mr. Fenwick undergoes treatment planning and localization for his radiation therapy at the comprehensive cancer center. The center radiation oncologist, who specializes in sarcoma treatment, creates an electronic "road-map" of Mr. Fenwick's radiation treatment for the local network provider. The cancer center and network radiation oncologists discuss the plan by telephone and agree to keep each other informed using the network electronic communication system. The system allows the cancer center's radiation oncologist to view x-ray images of the initial treatment simulation and the daily treatment

set up as the treatment progresses. Similarly, a community-based network medical oncologist is able to access the targeted chemotherapy developed at the cancer center and participate in the center's ongoing clinical trial. Mr. Fenwick receives his care at home and continues to work and interact with and receive support from his family during the 7-week course of preoperative therapy.

During the course of chemotherapy and radiation therapy, the nurses who are assigned to care for Mr. Fenwick reinforce information previously provided to Mr. and Mrs. Fenwick related to the treatment he is receiving; how to manage both expected and unexpected side effects, including ways in which certain side effects can be mitigated; and when they should call the practice and/or go to the emergency room. In addition, the nurses help manage Mr. Fenwick's various symptoms, such as nausea, vomiting, and fatigue, and provide recommendations for managing side effects to both the advanced practice nurse and physician according to the evidence-based PEP cards published by the Oncology Nursing Society. The nurses provide psychosocial support to Mr. Fenwick and his wife throughout the course of treatment.

Mr. Fenwick's preoperative therapy is successful. New diagnostic images show that the tumor has shrunk from 8 cm to 4 cm and is well away from the bone. Surgical resection at the comprehensive cancer center the following week includes wide margins clear of tumor cells.

The Fenwicks see the center's surgeon, radiation oncologist, and medical oncologist before leaving for home and being discharged back to Mr. Fenwick's primary care doctor and the local network medical oncologist. The oncologist discusses the evidence of a small survival benefit (about 6%) if he continues chemotherapy for 6 more months. In this circumstance, Mr. Fenwick, in consultation with his wife, decides that the benefit is too small to justify the expense, side effects, and potential disability. Nurse Brown provides information to the Fenwicks about what can be expected during the recovery period. This plan of care is coordinated and communicated to Nurse White in the primary care setting to which Mr. Fenwick will return. A consult to the rehabilitation service is initiated.

The network and center oncologists agree that this is a reasonable choice, and together they write a follow-up/survivorship care plan specifying frequency of visits, a testing schedule, symptoms to watch out for, and information about diet and exercise. The center's medical oncologist discusses the relative roles of the local oncology specialists and his primary care provider and assures Mr. Fenwick that he will continue to be available if needed. A copy of the clinical record, surgical and pathology reports, and survivorship care plan are sent electronically to Mr. Fenwick's primary care doctor, network oncologists, and referring general surgeon. Dr. Harding reviews the care plan and understands his role in surveillance to detect a recurrence or late effects of treatment. Dr. Harding reassures Mr. Fenwick that he will be in touch with the cancer center doctors if necessary and will continue to counsel him about other health prevention and health care needs. Mr. Fenwick's surgical site heals and allows him to return to work. Nurse White provides Mr. Fenwick with information about the signs and symptoms he should report to Dr. Harding. Occasionally, Mr. Fenwick asks Dr. Harding to consult with the surgical and medical oncologists at the comprehensive cancer center when he is concerned about a symptom such as an aching knee, but he remains cancer-free.

Discussion

Mr. Fenwick's clinical and psychosocial outcomes under the worst- and best-case scenarios are starkly different. The best-case scenario illustrates how a reliance on a multidisciplinary approach, evidence-based medicine, communication technology, and integrated systems of care can have a dramatic effect. The innovative "Shared Management Program" allowed Mr. Fenwick to receive state-of-the-art, high-quality care for his rare tumor through local oncology providers affiliated with specialists at the comprehensive cancer center. While the Fenwick family benefited greatly from this arrangement in psychosocial terms, the payers of care, including Mr. Fenwick, his employer, and his insurer, also benefited financially as a result of the lower cost of community-based care. The worst-case scenario

illustrates how the absence of these aspects of a care system contributed to Mr. Fenwick's poor prognosis, a devastated family with psychological and financial concerns, and health care providers facing legal challenges. Highlights of what went right and wrong in these alternative scenarios of Mr. Fenwick's care are outlined in Table 2 using the dimensions of quality care outlined by the IOM. Health care quality may be judged according to its safety, effectiveness, patient-centeredness, timeliness, efficiency, and equity.

Promoting Best-case Practices

Some steps to optimize care illustrated by this treatment scenario are outlined in Table 3.

CASE TWO: BREAST CANCER CARE

The Patient

Alice Aubrey consulted her internist, Dr. Raymond May, when her annual routine mammogram showed a small region of clustered calcifications in the upper outer quadrant of her right breast. Dr. May was unable to palpate any abnormalities during her breast exam but referred Mrs. Aubrey to a surgeon to rule out breast cancer. Dr. May had cared for the 78-year-old for many years and considered her to be in moderately good health, despite her chronic obstructive lung disease, hypertension, hypercholesterolemia, and osteoporosis, all well controlled with medication and diet. Mrs. Aubrey is accompanied during her visit to Dr. May by her daughter, who lives nearby and is actively engaged in her mother's care.

Mrs. Aubrey lives in a rural area served by a small community hospital that is part of the Care Alliance, a network of hospitals and outpatient clinics linked by a telemedicine demonstration project. Metropolitan Hospital is located 100 miles away and has recently advertised the opening of a new cancer center in the local paper. The state's university medical center takes a full day to reach.

A Worst-case Scenario

Mrs. Aubrey's daughter wants her mother to receive state-of-the-art cancer care and decides

TABLE 2 Case One: What Went Right/What Went Wrong

What Went Right Best-case Scenario	What Went Wrong Worst-case Scenario
Safety and Effectiveness	
Multidisciplinary approach to treatment planning Use of evidence-based clinical practice guidelines Referral to a high-volume center of excellence Access to clinical trials	Sequential treatment decisions made in isolation by specialty Definitive surgery prior to definitive diagnosis Treatment plan not based on best available evidence Surgery performed by inexperienced general surgeon Patient not informed of clinical trial for which he is eligible
Patient-centeredness	
High-quality, complex care provided close to home Family involvement at outset and throughout care continuum Care coordination by patient navigator Social work intervention to address psychological, financial, and employment issues Patient and caregiver treatment education and side-effect management provided initially and throughout the course of treatment Continued coordination of care when patient returned to facility closer to home Written treatment and follow-up plan given to patient	Patient required to repeatedly travel a great distance for care at the comprehensive cancer center Patient alone when informed of his cancer diagnosis and limited involvement of family in care decision making Complex cancer handled locally with no medical/psychosocial referrals Lack of attention to psychosocial issues and rehabilitation, especially those related to employment and finances No treatment education or appropriate or consistent symptom management No discussion of prognosis and issues pertaining to death and palliative care Reliance on oral communication without written treatment or follow-up plan
Timeliness, Efficiency, and Equity	
Cost savings accrued by providing complex care through local network providers affiliated with the comprehensive cancer center Communication of records electronically facilitates rapid transfer of information Care plan promotes efficient use of services, limits duplication Evidence-based care is available regardless of urban/rural residence because of evidence-based insurance coverage policies	Care provided solely at the comprehensive cancer center is costly and inconvenient for patient and family Several week delay in arranging surgical consultation following suspicious CT scan No written treatment or care plan to assist with timely course of treatment Insurers/payers have not initiated evidence-based coverage policies

to call Metropolitan Hospital so that they can be seen at the new cancer center. She does not realize (and is not informed) that appointments are made using a rotating list of surgeons developed by the hospital's marketing department. Participating surgeons volunteer to provide consultations in exchange for use of the hospital's diagnostic facilities. Mrs. Aubrey is given an appointment with one of the participating surgeons, Dr. Chester Williamson. In setting up the appointment, Mrs. Aubrey is informed that the film-screen mammogram performed at her community hospital is "archaic" and that a repeat study is needed with the cancer center's new digital unit with computer-aided detection. Mrs. Aubrey drives the 200-mile round trip with her daughter for the study that confirms the single area of calcification. Dr. Williamson calls Mrs.

Aubrey with the result and confirms the need for a biopsy. A core biopsy performed a week later demonstrates an invasive tubular carcinoma with a moderate amount of ductal carcinoma *in situ* associated with the invasive tumor.

At Mrs. Aubrey's third visit to Dr. Williamson, she is advised to have a complete staging work-up to make sure that the tumor has not spread before initiating local therapy. A bilateral breast magnetic resonance imaging (MRI); complete positron emission tomography (PET)/CT of the neck, chest, abdomen, and pelvis; and technetium-99 bone scan are performed 1 week later. The MRI detects a lesion that is potentially malignant in the left breast, but with a low degree of suspiciousness. The PET/CT is consistent with an abnormality in the upper outer quadrant of the right breast. It also shows an area of abnormality

TABLE 3 Case One: Steps to Optimal Care

Safety and effectiveness	<p>Providers of care</p> <ul style="list-style-type: none"> Practice collaborative care (eg, multispecialty consultation prior to definitive treatment) Consult evidence-based guidelines Consider centers of excellence for rare cancers Inform patients of relevant clinical trials Use electronic health records and foster their application to continuous quality improvement Provide a written summary of diagnosis, prognosis, and treatment plan to patients and all physicians involved in care Provide a survivorship care plan at the end of treatment to patients and all physicians involved in care Collaborate with and keep primary care providers informed throughout treatment and during survivorship Advocate for quality care through professional organizations <p>Insurers</p> <ul style="list-style-type: none"> Help coordinate clinically effective and cost-efficient programs for cancer care so that purchasers of insurance will be encouraged to select products and coverage options with benefits that encourage quality care <p>Policy makers</p> <ul style="list-style-type: none"> Promulgate policies to support quality cancer care (eg, providing incentives for interventions known to promote quality care, including evidence-based guidelines, electronic health records, and clinical trials) <p>Patients and families</p> <ul style="list-style-type: none"> Become an informed consumer with assistance from the National Cancer Institute, the American Cancer Society, and other organizations dedicated to educating the public about cancer Participate actively in care decisions Consider seeking a second opinion, especially from a comprehensive cancer center or specialist with particular expertise in your type of cancer
Patient-centeredness, timeliness, efficiency, and equity	<p>Providers of care</p> <ul style="list-style-type: none"> Engage the patient and family in decision making Provide formal patient and caregiver treatment education Routinely assess cancer patients and their caregivers for side effects and psychosocial distress and, when appropriate, refer to social work, mental health, or other support services Anticipate the effects of cancer on employment and health insurance and assist patients with disability and insurance issues Adopt programs to enhance timely and coordinated care (eg, patient navigation, electronic health information systems) <p>Insurers/payers</p> <ul style="list-style-type: none"> Help coordinate clinically effective and cost-efficient programs for cancer care so that purchasers of insurance will have available products and coverage options with benefits for symptom management, palliative care/hospice programs, telemedicine, patient education, patient navigation, psychosocial support services, and care/survivorship plans <p>Policy makers</p> <ul style="list-style-type: none"> Support patient navigation, electronic communication, and other programs that facilitate patient-centered care Promulgate policies that ensure equal access to evidence-based care <p>Patients and families</p> <ul style="list-style-type: none"> Ask health care providers and systems of care for help and support

in the low axilla that might represent malignancy but is also potentially a normal variant.

At their fourth visit, Dr. Williamson explains to Mrs. Aubrey and her daughter that since the finding in the left breast is neither palpable nor visible on mammogram, he recommends an attempt at ultrasound localization, hook-wire placement, and an open-excisional biopsy. The procedure is scheduled 1 week later. The ultrasonographer notes a suspicious finding (a vague

area of hypoechogenicity) where the MRI was positive. A wide local excision is performed under local anesthesia to make sure that the suspicious area is removed. The removed tissue is found to be benign (sclerosing adenosis). Mrs. Aubrey and her daughter are relieved but somewhat concerned that 6 weeks have elapsed since the initial visit to the cancer center. Mrs. Aubrey is upset because the biopsy was painful and left her breast mildly disfigured.

At this point, Mrs. Aubrey explains to Dr. Williamson that she would prefer to have a procedure that maximizes the quality of her life and minimizes additional lengthy trips to the cancer center. She wonders whether she could be cared for closer to home. A few of Mrs. Aubrey's friends had recovered well after having lumpectomies for their breast cancer, and she asks Dr. Williamson if this conservative treatment might be considered in her case. Dr. Williamson counsels against having a lumpectomy because he considers that her risk of recurrence would be too high. Instead, he recommends either a mastectomy or accelerated partial breast irradiation using a balloon radiation catheter. The latter approach would require 1 week of twice-a-day visits to the hospital's radiation oncology department. Considering the concerns Dr. Williamson expressed about the risk of recurrence, Mrs. Aubrey agrees to the accelerated partial breast irradiation. She and her daughter make reservations at a nearby motel so that they will not have to make the 200-mile trip to and from the hospital each day.

One week later, Mrs. Aubrey is admitted to the hospital. Because the PET scan suggested disease in the axilla, not only was the area of calcifications and a small margin removed (partial mastectomy) but also a dissection and removal of the lymph nodes in the underarm area. The pathologist reports that no disease could be seen at the margins of the tumor excised on examination of the frozen-section biopsies. The balloon catheter is then placed, and the patient is returned to the recovery room. Later that day, a CT scan is performed as part of the preradiation dosimetry. Unfortunately, the CT scan shows that the balloon catheter was placed too close to the skin to be used as the sole therapy and would cause significant skin damage. Since the catheter was placed, it was used for a single fraction of radiation as a boost to the local area before definitive radiation. The pathologist confirms the needle biopsy diagnosis of an 8 mm well-differentiated breast cancer. None of the 16 lymph nodes examined contained carcinoma. Mrs. Aubrey is discharged to home on the third postoperative day. Her sutures are removed 1 week later, and the following week she returns for her final postoperative visit.

A month later, following her recovery from surgery, Mrs. Aubrey returns to see the radiation oncologist, Dr. Eliot Lewis. He explains that because the partial breast irradiation was technically impossible, she needs conventional radiation. Mrs. Aubrey questions whether the radiation is really necessary, and Dr. Lewis informs her of results from clinical trials that indicate that without radiation therapy, her risk of local recurrence would be 35%. Fearful of such a recurrence, Mrs. Aubrey agrees to undergo conventional whole-breast irradiation. Dr. Lewis attempts to prepare Mrs. Aubrey for the external-beam treatment, but because of her axillary dissection, Mrs. Aubrey is unable raise her arm sufficiently to achieve the desired position for the planning phase of the radiation treatment. The set-up appointment is postponed to allow Mrs. Aubrey to recover more fully, and she returns 2 weeks later for the set up. Radiation treatment begins a week later and is completed in 5 weeks with daily therapy (25 fractions of radiation), traveling 200-miles round-trip daily.

Having completed the radiation treatment, Mrs. Aubrey is then referred to a medical oncologist, Dr. Robert Lawrence, who recommends the use of an aromatase inhibitor to decrease the risk of local recurrence, as well as to prevent the development of cancer in her other breast. The aromatase inhibitor causes a recurrence of her hot flashes (for which no therapy is recommended) and worsens her osteoporosis, for which she is given a bisphosphonate. In addition to these medication-related complaints and the biopsy-related deformity of her left breast, Mrs. Aubrey has persistent tenderness in her right chest, which leaves her with some limitation of arm movement.

While sitting in the waiting room of the medical oncologist for a follow-up visit, Mrs. Aubrey meets a patient her age with a similar breast tumor but who was treated by another surgeon with a partial mastectomy and tamoxifen alone. Mrs. Aubrey wonders whether all of her diagnostic and treatment interventions were necessary and seeks some answers by calling the American Cancer Society (ACS) information service. She asks Dr. Lawrence about her care and why it did not seem to conform with guidelines she found with the help of the ACS. Mrs. Aubrey did not receive satisfactory

answers, and she remains confused and embittered by her experience.

One month after the completion of her treatments, the bills begin to arrive. Medicare has accepted the medical rationale for all of the procedures and pays 80% of the charges, but Mrs. Aubrey is left responsible for the remaining 20% of the bill. Since the diagnostic procedures, hospital costs, and professional services approach \$60,000, she is shocked to learn that her copayment is \$12,000. With little savings, she seeks a second mortgage on her home. In addition to suffering lingering symptoms from her aggressive breast cancer treatment of questionable value, she is now saddled with mounting bills and financial worries.

A Best-case Scenario

Dr. May reviews Mrs. Aubrey's mammogram in consultation with the local hospital's diagnostic radiologist. Mrs. Aubrey is postmenopausal, and with atrophic breasts, the mammogram clearly shows calcification in the upper outer quadrant of the right breast that was not visible 1 year ago. Dr. May requests a review of the film by the mammography specialist serving the Care Alliance network, and he confirms the presence of 8 mm of microcalcifications and spiculation consistent with a malignancy.

The Care Alliance breast radiology specialist visits the local hospital 1 day a week to do stereotactic biopsies but recommends relying on ultrasound if the lesion can be localized ultrasonically. She points out that in such cases, an ultrasound-directed biopsy is as effective as a stereotactic biopsy in making a breast cancer diagnosis. Ultrasound localization and a core biopsy are performed the next day by the local radiologist. The local pathologist examines the core specimens and concludes that the tumor is well differentiated with associated ductal carcinoma *in situ*. The local pathologist's associate at the Care Alliance network also reviews the pathology and confirms this finding. Digital photographs of the histology and digitized images of the film-screen mammograms are entered into the Care Alliance electronic medical record (EMR) system.

Under the Care Alliance network agreement, all cancer cases are reviewed by a tumor board at

a consultative ACoS-approved hospital. Dr. May presents Mrs. Aubrey's history and physical exam, and the local pathologist and radiologist present their findings to the tumor board through the Care Alliance telemedicine system. Also in attendance at the tumor board "live" are the local hospital medical oncologist and surgeons. The mammogram is reviewed, felt to be technically adequate, and the network radiologist is confident that additional imaging in advance of local management would be of little benefit. There is agreement that the size and histological features of the neoplasm, as well as the estrogen receptor, progesterone receptor, and HER2/neu status, suggest a relatively nonaggressive behavior not warranting a bone or CT scan. The local medical oncologist, Dr. Lance Smith, and the network radiation oncologist, Dr. Charles Roach, both endorse the recommendation of an excisional biopsy and sentinel lymphadenectomy without additional imaging.

Dr. May discusses the tumor board's findings and recommendations with Mrs. Aubrey and refers her to his surgical colleague, Dr. Bill Charlson, who heads the local hospital's cancer committee and serves as the hospital's liaison to the ACoS Commission on Cancer. The next day (1 week after the needle biopsy and 2 weeks after her mammogram), Dr. Charlson meets with Mrs. Aubrey and her daughter. He explains the recommended treatment plan and provides information on how both the excisional biopsy performed under hook-wire/ultrasound localization and the sentinel lymphadenectomy are performed simultaneously as outpatient procedures. Dr. Charlson discusses the treatment plan and gives the family a written summary of the tumor board review. Mrs. Aubrey, with her questions satisfactorily answered, agrees to the treatment plan and schedules the procedure for the end of the week.

Before the day of her scheduled surgery, Mrs. Aubrey and her daughter have a patient treatment education session with the oncology nurse at the cancer center. The oncology nurse reinforces the information given to them by Dr. Charlson and provides additional, detailed information and instructions about the preoperative period and what can be expected in the immediate postoperative period. Mrs. Aubrey and her daughter are informed of a 24-hour, nurse-staffed

phone line available to them if they have questions following their visit.

The procedure is successfully completed, and Mrs. Aubrey returns a week later for follow up with Dr. Charlson. He provides Mrs. Aubrey and her daughter with the positive outcome of the procedure: the tumor was removed completely and the sentinel node was not cancerous. Dr. Charlson is pleased that Mrs. Aubrey has regained complete range of motion of her arm and that her breast incision is healing well. Dr. Charlson refers Mrs. Aubrey simultaneously to Dr. Smith, the medical oncologist who practices in the local community 3 days a week, and to Dr. Charles Roach, the radiation oncologist who practices in a free-standing center 50 miles away but who also performs consultations in Dr. Smith's office 1 day a week. The appointments are coordinated by Dr. Charlson's administrator so that Mrs. Aubrey can be seen on the same day at the local hospital 1 week later. The social worker assists with hotel accommodations and provides Mrs. Aubrey with information regarding her insurance coverage for these visits and potential treatments.

Mrs. Aubrey discusses with the medical oncologist her desire to maximize her quality of life as a cancer survivor but to minimize, if possible, additional medical interventions and doctor visits. Dr. Smith counsels Mrs. Aubrey regarding adjuvant therapy and explains that the latest evidence from randomized trials suggests that taking an aromatase inhibitor following lumpectomy markedly decreases the risk of recurrence to 4% to 7% from the 25% to 35% observed when an aromatase inhibitor is not taken following lumpectomy. He informs her that the addition of radiation would lower the risk of local recurrence further to 1% but cautioned that the overall survival rate is not improved by the addition of radiation. In a separate consultation, Dr. Roach confirms this information. He mentions that if she elected radiation treatment, he could use a fractionation program that would require 16 visits instead of the usual 25 to 28.

After the consultation with Drs. Smith and Roach, an oncology nurse meets with Mrs. Aubrey and her daughter to demonstrate a shared decision-making software tool developed to help patients with decisions about adjuvant therapy.

The nurse helps Mrs. Aubrey enter relevant clinical information into the hand-held computer and then assists her as she answers questions about quality-of-life and health care preferences. The program reinforces information about the risks and benefits of the alternative approaches and helps Mrs. Aubrey weigh her options in consideration of her values. The nurse also reinforces the information previously given to Mrs. Aubrey and provides a packet of written materials on breast radiation, tamoxifen, and aromatase inhibitors, and a list of Web site URLs that her computer-savvy daughter can access for additional information (including www.cancer.net, providing oncologist-approved cancer information; www.Komen.org, providing breast cancer information and advocacy; and www.RTAnswers.org, a Web site on radiation therapy). Drs. Smith and Roach each give Mrs. Aubrey a copy of their consultation notes and send copies electronically to Dr. Harding, Dr. Charlson, the network tumor board, and the hospital EMR system. Drs. Smith and Roach and the oncology nurse also give the patient and daughter their cards with office contact information and e-mail addresses in case they have additional questions.

A week later, with the help of her internist, Dr. May, Mrs. Aubrey decides that the additional absolute risk of 3% to 6% of a local recurrence (without evidence of a survival benefit) is not worth even the short 3-week course of radiation therapy offered by Dr. Roach. She calls to thank him for his honesty, and he reinforces her decision as "an entirely rational one." Mrs. Aubrey then begins a course of an aromatase inhibitor with Dr. Smith. Because of her long-term relationship with Dr. May, Dr. Smith works out a follow-up program in which most of the responsibility for monitoring the risk of local recurrence, metastatic spread, and side effects from the aromatase inhibitor are delegated to the internist, with the medical oncologist providing back up as needed. Mrs. Aubrey is aware that her risk of recurrence and death from this small breast cancer is minimal. She is not distressed by her cancer experience, but contact with another patient with breast cancer, a "Bosom Buddy," provides her with continued support and increases her interest in advocacy as a cancer survivor.

Discussion

In the worst-case scenario, Mrs. Aubrey travels thousands of miles and suffers physically and financially at the hands of physicians who appear to be more interested in financial gain and “market share” than in providing quality cancer care. The public often considers not getting enough care or “undertreatment” a hallmark of poor care, but as this scenario illustrates, poor care and outcomes can also follow from “overtreatment.” As the best-case scenario illustrates, excellent, “state-of-the-art” cancer care can be delivered close to home, even in a small rural community, when innovative technology and care system

alliances are used to facilitate evidence-based, multidisciplinary, coordinated care centered on the needs of local residents and utilizing the talents of local providers. Providing access to quality cancer care to individuals residing far from comprehensive cancer centers should be a matter of social justice and equity.

Highlights of what went right and wrong in these alternative scenarios of Mrs. Aubrey’s care are outlined in Table 4.

Promoting Best-case Practices

Some steps to optimize care illustrated by this treatment scenario are outlined in Table 5.

TABLE 4 Case Two: What Went Right/What Went Wrong

What Went Right Best-case Scenario	What Went Wrong Worst-case Scenario
Safety and Effectiveness	
An innovative telemedicine program allows evidence-based, multidisciplinary, coordinated care to be delivered at the community hospital close to home Quality checks are built into care planning (eg, multiple reviews of radiology and pathology results) Evidence-based, conservative interventions avoid treatment-related morbidity Reliance on a care alliance focused on quality improvement and affiliated with institutions approved by the American College of Surgeons Commission on Cancer	Patient’s family is misled by hospital newspaper advertisement describing its “state-of-the-art” cancer center Physicians appear to recommend diagnostic technologies and treatments based on financial gain rather than evidence of their effectiveness Unnecessary diagnostic procedures yield false-positive results. Overly aggressive treatment contributes to disability, bothersome symptoms, and disfigurement Single-discipline, noncollaborative, serial care planning instead of concurrent, multidisciplinary care planning contribute to poor treatment choices and delays System of care with no evident focus on quality of care
Patient-centeredness	
Physicians discuss treatment options, and nurse engages the patient and family in shared decision making with decision-support tools and patient information Patient receives written documentation of diagnosis, treatment, and follow-up plan Patient-expressed quality-of-life preferences are acknowledged and accommodated in the care plan Psychosocial support services are made available	Physicians do not adequately consider patient and family quality-of-life views and stated preferences in developing the care plan Treatment options are dictated with little opportunity for shared decision making Patient remains confused, embittered, and financially strapped at the conclusion of treatment Psychosocial assessment is not completed, and there is no discussion of available financial or support services
Timeliness, Efficiency, and Equity	
Care is provided in a timely fashion (3 weeks elapse from suspicious mammogram to completion of primary therapy), and patient is cared for close to home Diagnostic technology and treatments are used in a cost-effective manner The use of electronic medical records facilitates coordinated and timely care Primary care physician is integral to the development of the treatment and follow-up plan	Care is not coordinated and treatment is delayed (8 weeks elapse from the suspicious mammogram to completion of primary therapy), with over 7,000 miles traveled to care Inappropriate and duplicative use of technology and interventions contributes to excessive costs and financial burden for the patient Lack of an electronic medical record system contributes to poor communication, a lack of coordination, and delays in care Primary care is not integrated into the cancer care plan

TABLE 5 Case Two: Steps to Optimal Care

Safety and effectiveness	Providers of care	<p>Promote access to quality cancer care in local communities through innovative technology (eg, telemedicine) and alliances with centers with cancer expertise</p> <p>Use quality-improvement strategies (eg, radiology and pathology over-reads, participation in quality-oriented programs such as those of the American College of Surgeons Commission on Cancer)</p> <p>Practice collaborative care (eg, multispecialty consultation prior to definitive treatment)</p> <p>Practice according to evidence-based guidelines</p> <p>Use electronic health records and foster their applications to continuous quality improvement</p> <p>Provide a written summary of diagnosis, prognosis, and treatment plan to patients and all physicians involved in care</p> <p>Provide a survivorship care plan at the end of treatment to patients and all physicians involved in care</p> <p>Collaborate with and keep primary care providers informed throughout treatment and during survivorship</p> <p>Advocate for quality care through professional organizations</p>
	Insurers/payers	<p>Develop tools to help consumers identify cancer programs that embrace evidence-based care and quality improvement</p>
	Policy makers	<p>Promulgate policies to support quality cancer care (eg, providing incentives for interventions known to promote quality care, including evidence-based guidelines, electronic health records, telemedicine, and clinical trials)</p>
	Patients and families	<p>Become informed consumers with assistance from the American Cancer Society, the National Comprehensive Cancer Network, Susan G. Komen for the Cure, and other organizations dedicated to educating the public about cancer and its treatment</p> <p>Participate actively in care decisions</p>
Patient-centeredness, timeliness, efficiency, and equity	Providers of care	<p>Discuss quality-of-life issues and elicit patient preferences regarding treatment and engage the patient and family in shared decision making</p> <p>Provide formal patient and caregiver treatment education</p> <p>Routinely assess cancer patients and their caregivers for side effects and psychosocial distress and, when appropriate, refer to social work, mental health, or other support services</p> <p>Anticipate the effects of cancer on employment and health insurance and assist patients with disability, insurance, and financial issues</p> <p>Adopt programs to enhance timely and coordinated care (eg, telemedicine, patient navigation, electronic health systems)</p>
	Insurers/payers	<p>Help coordinate clinically effective and cost-efficient programs for cancer care so that purchasers of insurance will have available products and coverage options with benefits for symptom management, palliative care/hospice programs, telemedicine, patient education, patient navigation, psychosocial support services, and care/survivorship plans</p>
	Policy makers	<p>Support telemedicine, patient navigation, electronic communication, and other programs that facilitate patient-centered care</p> <p>Promulgate policies that ensure equal access to evidence-based care</p>
	Patients and families	<p>Ask health care providers and systems of care for help and support</p>

CASE THREE: RECTAL CANCER CARE

The Patient

Jorge Esteban was rushed to the local emergency room by his coworkers after he was found at his desk doubled up in pain. His wife had been encouraging him to seek help for the persistent abdominal discomfort he had been experiencing,

but the 53-year-old had resisted going to the doctor. He lacked health insurance and had hoped that the pain would go away on its own. The emergency room doctor quickly found the source of Mr. Esteban's pain, a large low rectal tumor.

Despite his poor rural upbringing in Guatemala and his struggles as a young undocumented worker on arriving in California 25 years ago,

Mr. Esteban has become a permanent US resident and succeeded as the owner of a small general contracting company. However, neither he nor his employees have health insurance coverage. The premiums associated with the group policies available through the business were too expensive for Mr. Esteban and his relatively low-wage employees.

Mr. Esteban has been married for 21 years and has 2 children aged 14 and 18 years. The Esteban family speaks mainly Spanish at home and receives episodic medical care at the local community hospital.

A Worst-case Scenario

Mr. Esteban is transferred from the local hospital's emergency department to the nearby university hospital where he is seen in consultation by a team of house officers, the medical oncology fellow, and one of a group of local surgeons who provide care to uninsured patients. The team confirms the presence of a 6 cm tumor within 7 cm and nearly blocking the external anal opening. A radiologic study identifies enlarged lymph nodes in the immediate vicinity of the tumor.

The physicians agree on a treatment plan to immediately deal with the near obstruction. They would first perform emergency intestinal bypass surgery and create a temporary colostomy and then later treat the tumor definitively. The house officer briefly explains the treatment plan to Mr. Esteban and then, as best he can, translates the operative consent form written in English into Spanish. Mr. Esteban signs the form but is confused about the cause of his abdominal pain and unsure of the meaning of "colostomy." He is taken to the operating room, and the bypass procedure is performed.

Following his recovery from surgery, Mr. Esteban starts a course of chemotherapy and is subsequently referred to a local radiation oncologist. While he is able to communicate with the Spanish-speaking nurse in the medical oncology clinic, he is unable to communicate with anyone at the radiation center and is both confused and fearful about the diarrhea, fatigue, and skin reaction that bother him during the 5.5 weeks of radiation treatment.

Four weeks after the completion of the radiation therapy, Mr. Esteban returns to the surgical clinic for follow up. The chemotherapy and radiation therapy had succeeded in shrinking the tumor, and the surgeon schedules Mr. Esteban for a tumor resection in 2 weeks. The surgeon removes the tumor and is able to spare any damage to the rectal sphincter. Unfortunately, however, the nerves that enervate penile erection must be removed with the tumor. Because the tumor is so close to the rectal sphincter musculature, the surgeon elects to keep the colostomy to divert the fecal stream, allow the connection to heal, and close the colostomy later. All of these eventualities had been explained to the patient before the surgery when the informed consent form was reviewed, but given the complexity of the discussion, the unsatisfactory translation of the form into Spanish, and his unfamiliarity with medical terms, Mr. Esteban has only a limited understanding of what occurred during the operation and what to expect afterward.

The pathologist concludes that the surgery effectively removed the tumor with clear margins but indicates that 6 of the 15 lymph nodes obtained with the specimen contained metastatic cancer. With evidence of metastases, the medical oncologist recommends additional chemotherapy. The pathologist's findings and the plan for additional chemotherapy are explained to the patient by the medical oncology fellow, but Mr. Esteban does not really understand why chemotherapy is necessary and is left fearing that the operation was not a complete success.

Over the next 6 months, Mr. Esteban adheres to the chemotherapy regimen, but the accompanying side effects take their toll, and he begins to dwell on the likelihood of lifelong disability and a premature death. He is ashamed to have his wife see him undress and lives with the mistaken belief that the colostomy is permanent. Adding to his growing sense of depression is his erectile dysfunction, which he is too embarrassed to discuss with his doctors. None of the doctors ask him about this or how the cancer and its treatment are affecting his life.

At the conclusion of his treatment, Mr. Esteban is told that he has no sign of cancer and that it is likely that he has been cured of his disease. He is relieved to learn that the colostomy was only

temporary and to have it surgically closed. He is, however, unprepared for the year-long period of embarrassment caused by his inability to control his bowel movements. Mr. Esteban's impaired sexual function continues to be a source of shame. He does not seek help for these problems because he assumes nothing would help. The lack of control he feels over his most basic bodily functions contributes to persistent distress, and eventually he becomes despondent and withdrawn. His previously successful business begins to fail as he loses interest in actively managing it. Mounting financial pressures, strained communications with his children, and a loss of the closeness and intimacy he shared with his wife contribute to a severe and prolonged depression.

A Best-case Scenario

A year ago, Mr. Esteban secured employer-based health insurance for his family with the assistance of a state-sponsored program. One of the program's counselors outlined available insurance options and facilitated the purchase of a plan suitable for his small contracting company. A managed care health maintenance plan (HMO) was chosen that had reasonably priced premiums and featured the availability of Spanish-speaking primary care physicians, advanced practice nurses, and social workers practicing as part of a collaborative team. At his first visit, David Hernandez, the advance practice nurse working with his primary care doctor, discussed ways for him to maintain his health, including getting checked for colorectal cancer after age 50 years. He had been alerted to the possibility of preventing colon cancer by an ACS informational spot that had aired during his favorite Spanish-language television program. Although hesitant to undergo the unpleasant-sounding test, Mr. Esteban, with the encouragement of Nurse Hernandez and his wife, decided to take advantage of this preventive screening test. Nurse Hernandez provides information about the colonoscopy preparation, answers questions about the procedure, and coordinates this procedure with the colonoscopy center nurse.

The colonoscopy performed a few weeks later revealed a tumor of the low rectum that appeared to be attached to the sacrum but not obstructing

his gastrointestinal tract. The results of the colonoscopy were entered into the HMO's EMR so that the surgeon and medical oncologist scheduled to see Mr. Esteban later that week would have all the information necessary to plan his treatment. In advance of his specialty appointments, Nurse Hernandez called Mr. Esteban to discuss the findings, elicit his concerns, and describe what to expect at his upcoming visit with the surgeon and medical oncologist. With the arrangements for clinical care made, Nurse Hernandez mentioned how valuable it often is to talk to a social worker familiar with cancer-related issues and the distress that often accompanies a cancer diagnosis. Mr. Esteban was encouraged to bring his wife to the upcoming visit and to request a visit with the social worker if desired.

Mr. Esteban, accompanied by his wife, listens to the recommendations of the surgeon and medical oncologist but has several questions that, with his limited English and lack of familiarity with medical terminology, are difficult to communicate to the doctors. A summary of the details regarding his diagnosis and the recommendation to administer preoperative chemotherapy and radiation are entered into the electronic record. Nurse Hernandez is able to access the summary from his office and then act as translator and facilitator to ensure that all of Mr. and Mrs. Esteban's questions are answered. Appropriate staging studies are performed, and the pathology results are subsequently communicated to the patient by the medical oncologist, with the assistance of Nurse Hernandez. Nurse Hernandez also helps Mr. Esteban make appointments for his chemotherapy and radiation therapy.

At both the chemotherapy and radiotherapy clinics, physicians communicate with the Estebans with the aid of Spanish-speaking nurses. The nurses also function as educators, providing Mr. Esteban with detailed information related to side effects that can be expected and how to manage them should they occur. The nurses also provide resources for dietary needs and emotional support. The Estebans receive a written summary that explains what treatments were administered, the anticipated immediate effects of treatment, potential late effects, and contact information for Spanish-speaking personnel in case of an emergency. Mr. Esteban

tolerates the chemotherapy and the radiation therapy without experiencing any unusual side effects. Nurse Hernandez follows Mr. Esteban's progress through messages received through the HMO's EMR system. He calls the Estebans periodically during treatment to ensure the effective management of treatment-related symptoms and to assess the family's distress levels and ability to cope.

Following the preoperative treatment, Mr. Esteban returns to the surgeon, who informs him that his response to treatment was excellent but that despite the administration of chemotherapy and radiation, there is evidence that some cancer remains. The surgeon informs Mr. Esteban that additional chemotherapy will be needed after the surgery. The tumor is removed, and it becomes apparent that a diverting colostomy is needed given the proximity of the excision to the lowest portion of the rectum and to the anus. Unfortunately, nerves controlling sexual function were embedded in fibrous extensions of the tumor and damaged as the tumor was being removed. The pathologist examining the removed tissue concludes that the proximal, distal, and radial margins are clear and that 4 of the 15 lymph nodes contain cancer.

The medical oncologist and Nurse Hernandez visit Mr. and Mrs. Esteban in the hospital following the procedure to review the pathology findings and discuss the need to administer additional chemotherapy to decrease the likelihood of a recurrence of the cancer. With this additional treatment, they inform Mr. Esteban of his excellent chance of having his cancer cured and a complete recovery. When he is discharged from the hospital, the nurse provides Mr. Esteban with a written updated treatment plan and information on what to expect after surgery, management of side effects, and a follow-up plan that includes appointments for wound checks. The surgeon explains the potential for erectile dysfunction and gives Mr. Esteban the name of a urologist in case the problem occurs.

At Mr. Esteban's follow-up primary care visit, Nurse Hernandez reinforces the surgeon's conclusions and recommendations, reviews instructions on maintenance of the temporary colostomy, and discusses Mr. Esteban's fears about sexual dysfunction.

Mr. Esteban tolerates his additional chemotherapy without significant problems. At the completion of the chemotherapy, the medical oncologist gives Mr. Esteban an updated treatment summary and a detailed survivorship document (in Spanish) explaining the entire treatment course and outlining how he would be followed by the primary care physician and nurse, the medical oncologist, the surgical oncologist, and the radiation oncologist. Mr. Esteban had been informed that the treatments might be debilitating in the short term, so he made arrangements for his brother and his foreman to maintain the business. As his strength and stamina improved, he returned to work helping his brother and the foreman supervise at the job site.

With the colostomy reversed following the chemotherapy, Mr. Esteban is seen by a nurse at a rehabilitation clinic. The Kegel exercises he learned there aided his recovery and rectal function. He discusses his sexual dysfunction with Nurse Hernandez and is prescribed a drug to help with his erections. Nine months after his surgery, Mr. Esteban is cancer-free, back at work, and fully functional.

Discussion

The elements of Mr. Esteban's clinical care do not markedly differ in this best- and worst-case scenario. It is the identification of the rectal tumor a year earlier in the best-case than in the worst-case scenario that improves Mr. Esteban's likelihood of survival. Enrollment in a health insurance program facilitated access to primary care, and community-based cancer education encouraged the uptake of recommended colorectal screening. The second major difference between the best- and worst-case scenarios is the full integration of primary care with the complex oncology care "system." Nurse Hernandez, the primary care advance practice nurse, provided translation services, patient navigation, patient-treatment education, symptom-management information, psychosocial assessment, and counseling. In so doing, he ensured the delivery of culturally sensitive care.

Highlights of what went right and wrong in these alternative scenarios of Mr. Esteban's care are outlined in Table 6.

TABLE 6 Case Three: What Went Right/What Went Wrong

What Went Right Best-case Scenario	What Went Wrong Worst-case Scenario
Safety and Effectiveness	
Prevention awareness occurs at multiple levels (primary care team, media) to foster use of cancer screening Earlier identification of cancer improves likelihood of survival	Lack of access to primary care limits ability to reinforce community-based cancer prevention messages Without screening, cancer is more advanced and treatment less likely to be effective
Patient-centeredness	
Early and ongoing discussion and monitoring of psychosocial concerns Family involvement in care is encouraged Availability of Spanish-language personnel as part of the care team aids communication of complex information Provision of patient treatment education information, written treatment, follow up, and survivorship plan assists patient and primary care team in effectively managing treatment effects Patient navigation assists family with complex cancer care system	Lack of attention to psychosocial concerns contributes to very poor mental health, social, and employment outcomes Patient is alone during most medical visits and without family support has trouble understanding his treatment and prognosis Without adequate translation, patient is left confused about his cancer, treatment, and prognosis Limited provision of education regarding treatment, symptom management, and prognosis contributes to misunderstanding and untreated treatment-related symptoms Little guidance provided to aid patient and family as they face a lengthy, complex course of treatment and recovery
Timeliness, Efficiency, and Equity	
State-sponsored program provides information and administrative support to small business, encouraging enrollment Insurance coverage facilitates early entry into medical system and access to primary care Use of electronic medical record permits rapid transfer of information and timely care Collaborative care model permits integration of primary care and oncology care, leading to an efficient use of health personnel and coordinated care	The complexities and costs of private health insurance discourage enrollment A lack of insurance coverage contributes to late diagnosis and delayed treatment The slow flow of paper records impedes communication between primary care, specialists, pathology, and imaging technologists Without involvement of the primary care advance practice nurse, patient does not receive coordinated care

Promoting Best-case Practices

Some steps to optimize care illustrated by this treatment scenario are outlined in Table 7.

CASE FOUR: POST-TREATMENT SURVIVORSHIP CARE

The Patient

Christina Jones is a 50-year-old survivor of Stage IV-B Hodgkin disease. Her initial treatment at the age of 24 years consisted of surgery to remove her spleen and to move her ovaries behind the uterus, away from the planned field of irradiation, in an effort to preserve fertility. Surgery was followed by 6 months of lymph node radiation. One year after the completion of her initial therapy, she had emergency surgery to remove radiation-induced adhesions that were obstructing her small bowel. Twelve years later, Mrs. Jones had a recurrence of Hodgkin disease

with the same histology. She was treated with 4 cycles of MOPP chemotherapy (a combination of mustargen, vincristine [also called Oncovin], procarbazine, and prednisone). Although 6 cycles of chemotherapy were recommended according to established protocols, Mrs. Jones elected to stop after 4 cycles because of nerve damage (peripheral neuropathy caused by the chemotherapy vincristine). The resulting "foot drop" contributed to persistent difficulties in walking. Mrs. Jones was left infertile by the treatment. She has been cancer-free for 14 years.

Mrs. Jones completed treatment for her initial and recurrent cancer in a Northeastern comprehensive cancer center. She now lives on the outskirts of a midsized southern town and sees a primary care physician and gynecologist for her ongoing medical needs.

Mrs. Jones is married and is caring for her critically ill husband. The demands of caregiving forced her to quit her job 2 years ago.

TABLE 7 Case Three: Steps to Optimal Care

Safety and effectiveness	<p>Providers of care</p> <ul style="list-style-type: none"> Support the development and implementation of culturally sensitive cancer prevention and early-detection public education programs Promote interventions to improve health care provider's adherence to evidence-based cancer prevention and early-detection guidelines
	<p>Insurers</p> <ul style="list-style-type: none"> Help coordinate clinically effective and cost-efficient programs for cancer so that purchasers of insurance will be encouraged to select products and coverage options with benefits for cancer prevention and early detection
Patient-centeredness, timeliness, efficiency, and equity	<p>Policy makers</p> <ul style="list-style-type: none"> Promulgate policies to support quality cancer care (eg, providing incentives for interventions known to promote quality care, including evidence-based guidelines, cancer prevention programs, and research)
	<p>Providers of care</p> <ul style="list-style-type: none"> Advocate for policies and programs to expand access to health insurance coverage Adopt programs to enhance timely, coordinated, and culturally sensitive care (eg, collaborative care teams, translation services, patient navigation, electronic health information systems) Provide formal patient and caregiver treatment education Routinely assess cancer patients and their caregivers for symptoms, side effects, and psychosocial distress and, when appropriate, refer to social work, mental health, or other support services Equip cancer patients and their health care providers with a treatment and survivorship care plan that includes information needed to understand the diagnosis and treatment, and then anticipate, identify, and manage cancer's late effects Support primary care providers in their role in cancer care Assist in the development of information systems that help ensure effective communication within care systems
	<p>Insurers/payers</p> <ul style="list-style-type: none"> Help coordinate clinically effective and cost-efficient programs for cancer care so that purchasers of insurance will have available products and coverage options with benefits for symptom management, palliative care/hospice programs, telemedicine, patient education, patient navigation, psychosocial support services, and care/survivorship plans Create incentives to encourage providers to adopt systems that foster patient-centered, timely, and efficient care (eg, electronic health information systems, collaborative care teams, treatment and survivorship plans)
	<p>Policy makers</p> <ul style="list-style-type: none"> Develop policies to expand access to health insurance Create incentives within health care systems that foster quality care
	<p>Providers of care</p> <ul style="list-style-type: none"> Advocate for policies and programs to expand access to health insurance coverage Ask health care providers for written treatment and survivorship care plans that include information on rehabilitative care and how to access psychosocial support services

A Worst-case Scenario

Mrs. Jones has gained 30 pounds in the past few years while caring for her husband at home. She visits her primary care physician, Dr. Bender, to report troublesome symptoms, including shortness of breath, anxiety, difficulty swallowing, sleep disturbance, and pain in her arms and legs. Dr.

Bender acknowledges Mrs. Jones difficult home situation and prescribes an antidepressant, antianxiety medication, and sleeping pills. To alleviate what appear to be menopausal symptoms, he prescribes hormone replacement therapy. He also recommends regular exercise and a healthy diet to get her weight under control. Mrs. Jones, worried that her cancer may have returned, presses

Dr. Bender to run some tests. Her weight gain seems unusual and has occurred despite her exercising and general loss of appetite. Dr. Bender reassures Mrs. Jones and promises to conduct tests if her health does not improve in 3 months.

Mrs. Jones returns to see Dr. Bender 3 months later and reports that her symptoms have not improved. In fact, the shortness of breath and difficulty swallowing have worsened, leaving her frightened and feeling desperate. Her concerns were heightened on learning from an online listserv that several other long-term Hodgkin disease survivors were experiencing similar symptoms. Dr. Bender reassures Mrs. Jones, reiterating his opinion that the stress of caregiving is likely the primary problem. He orders blood tests and a chest x-ray in an effort to alleviate her concerns.

Dr. Bender's secretary calls Mrs. Jones to let her know that her thyroid function is sluggish and gives her a prescription for Synthroid. The secretary also tells Mrs. Jones that Dr. Bender wants her to make an appointment to see a cardiologist to have additional tests performed because her chest x-ray shows some heart enlargement. With her husband actively dying, Mrs. Jones puts off seeing the cardiologist, as the recommendation from the office secretary does not seem of an urgent nature. A few weeks later, Mrs. Jones collapses while walking her dog. She is found by a neighbor and taken to the emergency room, where she is admitted having suffered a heart attack. While recovering from the attack, she is seen on rounds by an oncologist, who on noting her cancer history, orders scans that uncover spinal degeneration involving lumbar and cervical discs. A mammogram reveals breast calcifications, and the oncologist orders a follow-up consultation. While she is hospitalized, a home care nurse is hired to attend to Mrs. Jones' dying husband. Facing an onslaught of bad news regarding her own health and the imminent demise of her husband, Mrs. Jones is burdened emotionally, spiritually, and financially. A social worker is called in to help manage the case.

A Best-case Scenario

Eight years ago, at age 42 years, Mrs. Jones received a letter from the cancer center where she was originally treated that described a new program called Keep Survivors Surviving (KESS).

Research had shown that cured, young, Hodgkin disease survivors were at high risk of experiencing serious late- and long-term effects of their cancer treatment. The KESS program provided her with a summary of her diagnosis and treatment and information about resources that she and her primary care doctor could use to develop a plan for follow up that would be appropriate given her history of cancer.

Dr. Bender, her primary doctor since her move to the South, logs onto the KESS Web site. After entering her age and information pertaining to her diagnosis and treatments, he is able to generate a survivorship follow-up care plan. The plan is tailored to Mrs. Jones cancer history and includes a schedule for specific blood tests, x-rays, and cardiovascular assessments. It also provides a useful guide to other medical and psychosocial services. Dr. Bender recalled from his training that hypothyroidism was common after radiation but was surprised to learn that the relative risk of thyroid cancer, cardiovascular disease, soft tissue sarcoma, and breast cancer far exceeded what would be expected in a 42-year-old woman without her cancer treatment history. The KESS Web site provided valuable contact information for oncologists specializing in cancer survivorship, allowing Dr. Bender to discuss Mrs. Jones' follow-up plan with local experts. Nurse Smith, an oncology nurse with the KESS program, reviews the suggested follow-up care plan with Mrs. Jones and emphasizes what Mrs. Jones should bring to Dr. Bender's attention. She encourages Mrs. Jones to contact her or Dr. Bender with any questions or concerns.

The initial battery of recommended tests indicates low thyroid function, and Mrs. Jones begins thyroid replacement therapy. Given her heightened risk of heart disease, Dr. Bender decides to prescribe a statin drug to lower her minimally elevated cholesterol levels. With no family history of heart disease, Mrs. Jones would not have been a candidate for this drug had it not been for her particular treatment history. He also sends her to a breast cancer specialist to evaluate whether her current yearly mammogram schedule is adequate. The agreed-on intensified breast cancer detection regimen includes the use of MRI scans, which aid in diagnosing a very early breast cancer. Nurse Smith confirms that Mrs. Jones understands the purposes of the tests and what is

involved in having the tests and makes it clear that additional information will be provided as part of the informed-consent process. As the survivorship plan is discussed, the nurse reviews in detail the schedule, potential outcomes, financial considerations, and the importance of appropriate follow up.

At age 47 years, as her household duties increase because of her husband's serious illness, Mrs. Jones finds that she has to stop several times while making the bed because of shortness of breath. Mrs. Jones' survivorship care plan has alerted her to this symptom and prompts her to seek immediate medical attention. Dr. Bender orders an echocardiogram and cardiology consultation. Her ejection fraction is abnormally low at 35%, and the stress test is inconclusive. A cardiac catheterization shows 3-vessel coronary disease. Mrs. Jones' symptoms improve considerably with medical management, but she undergoes regular monitoring by the cardiologist. Dr. Bender helps Mrs. Jones intensify her cardiac prevention efforts. Mrs. Jones decides to quit her job in order to devote more time to her husband as his health fails. Nurse Smith reinforces information about her new cardiac diagnosis and how it could be related to her previous treatment so that Mrs. Jones can understand the current therapy and how it relates to her underlying condition. The oncology nurse explains the possible side effects of the current treatment and how the symptoms will be monitored and informs Mrs. Jones about when she should contact the practice and/or seek urgent care. The oncology nurse provides appropriate symptom management in collaboration with Dr. Bender.

The KESS program includes an online chat room so that Mrs. Jones can discuss her medical, psychological, and health insurance experiences with others with a similar background. A social worker who monitors the online discussions provides advice on how to manage the stress and anxiety related to her heightened awareness of her health risks. She also helps Mrs. Jones ensure continuity of health insurance coverage after she leaves her job to care for her husband.

Discussion

Mrs. Jones' health and psychosocial outcomes under the worst-care scenario represent every

patient's nightmare. The well-documented long-term risks associated with her cancer treatment are not understood in that context by her primary care physician. Her health deteriorates in the absence of intervention and prevention. Despite her best efforts to relay information she has acquired from her peers, she is not able to convince her doctor that prompt action is needed. Under the best-case scenario, it was the outreach effort of the oncology team at the comprehensive cancer center that assured Mrs. Jones' improved outcome. The KESS survivorship program served as a teaching tool for her primary care provider. Its online features provided information on late effects and links to cancer survivorship expertise that aided him as he planned and implemented her follow-up care.

The KESS program adhered to the recommendations of the IOM's report, *From Cancer Patient to Cancer Survivor: Lost in Transition*.⁶ The IOM committee issuing the report recommended that patients completing primary treatment be provided with a comprehensive care summary and follow-up plan that is clearly and effectively explained. This "Survivorship Care Plan" should be written by the principal provider(s) who coordinated oncology treatment. The service should be reimbursed by third-party payers of health care. The IOM committee also recommended that health care providers use systematically developed, evidence-based clinical practice guidelines, assessment tools, and screening instruments to help identify and manage late effects of cancer and its treatment.

Highlights of what went right and wrong in these alternative scenarios of Mrs. Jones' care are outlined in Table 8.

Promoting Best-case Practices

Some steps to optimize care illustrated by this treatment scenario are outlined in Table 9.

CASE FIVE: END-OF-LIFE CARE

The Patient

Rosa Pazzo is a 42-year-old Italian-American with advanced-stage breast cancer that has metastasized to her spinal cord. Mrs. Pazzo has been receiving various forms of aggressive

TABLE 8 Case Four: What Went Right/What Went Wrong

What Went Right Best-case Scenario	What Went Wrong Worst-case Scenario
Safety and Effectiveness	
Keep Survivors Surviving program allows primary care provider to manage survivorship care through Web-based patient-specific follow-up care plans Preventive interventions and early identification and management of late effects improve clinical and psychosocial outcomes	Primary care provider lacks readily available tools help him identify cancer-related post-treatment health problems Late effects are not identified early, resulting in poor clinical and psychosocial outcomes
Patient-centeredness	
Information and support available through Keep Survivors Surviving Web-based tools alleviate stress and anxiety Contact with social workers facilitates health insurance continuity	No referral to counseling and support resources to address patient anxiety and stress Assistance with home care services not provided when patient's symptoms began to interfere with care-giving responsibilities
Timeliness, Efficiency, and Equity	
Prospective care plan permits the timely identification and management of hypothyroidism, cardiac dysfunction, and early breast cancer Primary care management of survivorship care represents an efficient use of health care services	Delay in cardiology consultation results from miscommunication between office staff and patient

chemotherapy and, most recently, radiation therapy to try to relieve a painful spinal cord compression. Mrs. Pazzo has failed to respond successfully to all past chemotherapy, and her tumor is showing no response to her current course of therapy. Mrs. Pazzo is practically bedridden and very symptomatic. Her physical ability to continue her chemotherapy is a concern to her medical oncologist, Dr. Smyth.

Mrs. Pazzo resides in the Northeast and is supported by a husband, Victor, 2 small children, and a large extended family. Mrs. Pazzo and her family are devout Catholics.

A Worst-case Scenario

Dr. Smyth is paged by the emergency room staff in the middle of the night to inform him that Mrs. Pazzo has been transported via ambulance to the emergency room. Mrs. Pazzo's family caregivers have been unable to alleviate her extreme pain, and she arrives hysterical and in need of sedation. Dr. Smyth tells the emergency room staff to admit Mrs. Pazzo to the medical-surgical unit and to inform the family that he will see her the next day during his rounds at the hospital.

The next morning, Dr. Smyth meets with Mr. and Mrs. Pazzo in her hospital room to

discuss her plan of treatment. Although Dr. Smyth tells them that Mrs. Pazzo's tumor "appears to be slow to respond to the treatment," the couple is adamant that treatment be continued "for the sake of the children." The couple is highly emotional, and Dr. Smyth feels it is best to abide by their wishes as they are obviously not in the "right state of mind" to rationally discuss her poor prognosis and a recommendation for hospice care. Besides, Dr. Smyth believes that Mrs. Pazzo desperately needs radiation therapy for her spinal cord compression and is under the impression that a move into a hospice would make her ineligible for any further radiation. Running late for clinic, he does not have time to check with the social work department regarding the use of palliative radiation in hospice.

For the next several weeks, Mrs. Pazzo's condition worsens, and her extended family keeps vigil by her bedside. Mrs. Pazzo begs her family not to bring her children to the hospital, as she does not want to upset them. All of the family members are extremely agitated by her failing health, and the nurses become impatient with their constant demands. Mrs. Pazzo is moved to the intensive care unit, where Dr. Smyth informs the family that her fragile state

TABLE 9 Case Four: Steps to Optimal Care

Safety and effectiveness	Providers of care	<ul style="list-style-type: none"> Promote the development of organized survivorship programs within hospitals and other systems of care Equip cancer survivors and their health care providers with a survivorship care plan that includes information needed to anticipate, identify, and manage cancer's late effects Support primary care physicians in their role in post-treatment cancer care Assist in the development of information systems that help ensure cancer survivors receipt of appropriate surveillance Advocate for the development of evidence-based survivorship guidelines Participate in the development and dissemination of professional education programs on cancer survivorship
	Insurers	<ul style="list-style-type: none"> Adopt reimbursement policies that encourage quality care, including coverage for survivorship care planning and related services
	Policy makers	<ul style="list-style-type: none"> Promulgate policies to support quality cancer care (eg, providing incentives for interventions known to promote quality care, including evidence-based guidelines, survivorship programs, and research)
	Patients and families	<ul style="list-style-type: none"> Become informed consumers with assistance from the National Coalition for Cancer Survivorship, the Lance Armstrong Foundation, and other organizations dedicated to educating the public about cancer survivorship Ask cancer care providers for a cancer survivorship care plan to guide post-treatment care Consider reaching out to other cancer survivors to share experience and provide support
Patient-centeredness, timeliness, efficiency, and equity	Providers of care	<ul style="list-style-type: none"> Anticipate the late effects of cancer and assure their prompt identification and management Provide formal patient and caregiver treatment education Routinely assess cancer patients and their caregivers for side effects and psychosocial distress and, when appropriate, refer to social work, mental health, or other support services Adopt programs to enhance timely and coordinated care (eg, dedicated survivorship programs, patient navigation, electronic health information systems)
	Insurers/payers	<ul style="list-style-type: none"> Help coordinate clinically effective and cost-efficient programs for cancer care so that purchasers of insurance will have available products and coverage options with benefits for symptom management, palliative care/hospice programs, telemedicine, patient education, patient navigation, psychosocial support services, and care/survivorship plans
	Policy makers	<ul style="list-style-type: none"> Support survivorship care programs and innovative ways to deliver such programs
	Patients and families	<ul style="list-style-type: none"> Ask health care providers for survivorship care plans that include information on how to access psychosocial support services

will no longer allow her to continue her chemotherapy treatments. The family is despondent but remains hopeful that Rosa will “rally” and be able to get back on course with her curative therapy treatments.

Mrs. Pazzo lives for 3 more weeks in the intensive care unit. Unable to drink or eat and in terrible pain, Mrs. Pazzo is kept heavily sedated and in a semicomatose state. Mrs. Pazzo's organs begin to fail, and she goes into cardiac arrest while several family members are in her room. After multiple attempts by the physicians to resuscitate her, she dies of cardiac arrest on her daughter's

sixth birthday and before her parish priest can be reached to administer Last Rites.

A Best-case Scenario

With progression of her disease through her initial round of chemotherapy, Dr. Smyth discusses with Mrs. Pazzo the need to consider all aspects of her health and her plans for the future. Dr. Smyth schedules a visit for Mrs. Pazzo and her husband to discuss advance-care planning with June Forth, a nurse practitioner, and Karen Winters, a social worker, both affiliated with the

practice. During the consultation, Mrs. Pazzo has the opportunity to discuss her beliefs and concerns related to death and dying, what it means to live well, her end-of-life priorities, and the importance of family and the church in meeting her psychosocial needs.

At the following clinic visit, Karen Winters meets with Mr. and Mrs. Pazzo to assess the Pazzos' level of understanding of Mrs. Pazzo's clinical status, to evaluate the couple's level of psychosocial distress, to discuss further Mrs. Pazzo's preferences for end-of-life care, and to review and complete advance directives that codify her end-of-life preferences. Subsequently, the social worker, Nurse Forth, and Dr. Smyth spend 2 hours meeting with Mr. and Mrs. Pazzo and members of the extended family to review the treatment plan. In addition to discussing the clinical aspects of the plan, the health care team evaluates the family's emotional state, their values, and their current understanding of Mrs. Pazzo's condition and her prognosis. After the meeting, the care team concludes that the family lacks an overall understanding of Mrs. Pazzo's condition and that open dialogue and supportive emotional care will be vital to the family's well-being. It is determined by the care team that the family would benefit from a palliative care consultation.

For the next few weeks, Mrs. Pazzo receives aggressive treatment for her symptoms and continues both her radiation therapy and her chemotherapy. The care team has arranged for a palliative care consult on her next inpatient visit when members of the extended family will be in attendance. Mrs. Pazzo has developed a bond with Nurse Forth and begins to talk openly to her about her fears of dying, of leaving her children, and of hurting her extended family. Nurse Forth encourages these conversations and suggests to Mrs. Pazzo that she meet with the social worker and members of the palliative care team to explore, and begin to address, these feelings. Mr. and Mrs. Pazzo, Rosa's parents, and her parish priest also meet to talk. In collaboration with the palliative care team and Dr. Smyth, Mrs. Pazzo and her family discuss her care options and decide that she should stop the chemotherapy and radiation therapy. The palliative care team continues to care for Mrs. Pazzo and her

family and arranges for her to meet with a representative from hospice. Mrs. Pazzo is subsequently admitted to a home-based hospice program. Pain control management is continued. However, Mrs. Pazzo becomes debilitated by a metastasis to her spinal column. Palliative radiation therapy treatments are ordered to manage the pain of her spinal cord compression.

For the next few weeks, Mrs. Pazzo remains at home and receives daily visits from her family. On the suggestion of the social worker, Mr. Pazzo sets up a schedule that allows his wife to see 2 to 3 members of her extended family each day for a short time, which also enables her to have the time and energy to spend each day with her children. Without the chemotherapy, Mrs. Pazzo's debilitating nausea and vomiting, fatigue, and other symptoms lessen, allowing her some quality time. Mrs. Pazzo meets with her spiritual counselor regularly and receives visits from her parish priest every other day. The hospice care providers coordinate help from volunteers from her church and home health services.

With the continued support of her hospice care providers, her plans and goals are reevaluated, and the sixth birthday of her daughter is identified as a primary goal. Although Mrs. Pazzo's health is failing, she is determined to see her daughter's sixth birthday, and on that day, her parents, husband, and her 2 children gather at her home for a quiet celebration—except for the raucous rendition of “Happy Birthday” sung by members of the hospice team. With the help of one of the hospice nurses, Mrs. Pazzo manages to sip some of her beloved Merlot from a sponge and swallow bits of mashed-up chocolate birthday cake.

Two days later, Mrs. Pazzo's organs begin to fail. Her hospice team makes sure that her pain is adequately controlled according to her wishes and as specified in her advance directive. The staff honor her “do-not-resuscitate” order. Mrs. Pazzo's parish priest is summoned to administer Last Rites and does so in the company of her husband and her spiritual counselor. Mrs. Pazzo dies peacefully at home a day later with her husband and her family by her side while listening to a CD of her children's favorite songs playing in the background.

TABLE 10 Case Five: What Went Right/What Went Wrong

What Went Right Best-case Scenario	What Went Wrong Worst-case Scenario
Safety and Effectiveness	
Palliative care professionals focus on addressing Mrs. Pazzo's pain and symptoms Pain and other symptoms are promptly managed The goal of living to her daughter's sixth birthday is met	Curative care strategies are pursued without discussion of palliative care options Chemotherapy of questionable therapeutic benefit is administered Medical oncologist unaware that palliative radiation treatment is permissible in hospice No referrals made to palliative care specialty providers or services Pain and suffering compromise quality of life and preclude visits with children at the end of life
Patient-centeredness	
With pain controlled, patient is able to express concerns, voice wishes pertaining to her death, and participate in decisions regarding care (including completion of advance directives) Care team meets family needs for information and emotional support Spiritual needs are met and Last Rites are administered Preferences for end-of-life care are acted upon and death occurs at home	With pain uncontrolled, patient is unable to voice preferences or participate in decisions about care Patient's family placed in the position of directing care without counseling related to her prognosis and care options No referral to social work services is made despite high levels of distress Spiritual needs are unmet Preferences for end-of-life care are not elicited, and death occurs in hospital
Timeliness, Efficiency, and Equity	
Advance care planning instituted early Nurse and social worker experienced in end-of-life care integrated into oncology practice The need to coordinate care is recognized early and transitions from home care to palliative care and finally to home hospice care are well coordinated and "seamless" The care setting is appropriate to meet palliative care goals	With poorly managed pain, care is inefficiently managed in "crisis" mode, and patient transitions from the ER to inpatient care and finally to intensive care, where futile medical care is administered Expensive in-hospital medical resources are inappropriately used given patient's terminal state

Discussion

All health care professionals are duty-bound and motivated to alleviate their patients' pain and suffering. In this worst-case scenario, we see how health care system failures leave Mrs. Pazzo suffering from pain and other cancer symptoms. As the best-case scenario illustrates, focusing early on palliation, setting appropriate treatment goals with patients and families, attending to psychosocial issues, collaborating with palliative care providers, and marshalling end-of-life care specialists can lead to marked improvements in quality of care and quality of life and to a more efficient use of resources. Highlights of what went right and wrong in these alternative scenarios of Mrs. Pazzo's care are outlined in Table 10.

Promoting Best-case Practices

Some steps to optimize care illustrated by this treatment scenario are outlined in Table 11.

CONCLUSION

The actions of individual providers and patients and families during the course of care are key to improving quality cancer care. However, recognizing that worst-case care generally represents a shortcoming of systems and policies, efforts are needed to address these systemic problems.

Anyone reading these cancer care case studies would want their care to follow the best-case scenarios. It is relatively easy to see what went wrong in the worst-case scenarios, which raises the question, "Why do people continue to receive worst-case care?" All health care providers want to administer best-case care but find themselves in systems of care that impede their best intentions. Inadequate clinical information technology, incomplete evidence on best practices, staffing shortfalls, complex reimbursement policies, administrative burdens, and other systems barriers frustrate providers' best efforts to provide quality care.

TABLE 11 Case Five: Steps to Optimal Care

Safety and effectiveness	Providers of care	Take time to set realistic treatment goals with patients and their families. Discuss end-of-life preferences early in the care process. Identify resources necessary to promptly manage cancer symptoms and minimize futile care Integrate professionals (eg, advance practice nurses, social workers) with expertise in end-of-life care into oncology practices Support the development of palliative care teams and expertise within care settings Collaborate with palliative care and end-of-life care providers to develop seamless transitions of care Learn about hospice benefits so that they can be appropriately used Seek training in the management of end-of-life care
	Insurers/payers	Adopt reimbursement policies that encourage quality end-of-life care
	Policy makers	Promulgate policies to support quality end-of-life care (eg, providing incentives for interventions known to promote quality care, including evidence-based palliative care guidelines and clinical trials)
	Patients and families	Become informed consumers with assistance from the National Cancer Institute, the American Cancer Society, the National Hospice and Palliative Care Organization, and other organizations dedicated to educating the public about cancer care at the end of life Complete advance directives to codify the scope of services desired at the end of life
Patient-centeredness, timeliness, efficiency, and equity	Providers of care	As part of patient counseling, identify aspects of quality of life that are important to patients and families. Focus care on meeting patient goals and realization of preferences When psychosocial distress is evident, promptly arrange for social service intervention Arrange for spiritual care intervention when spiritual distress is evident Adopt programs to enhance timely and coordinated care (eg, patient navigation, electronic health systems)
	Insurers	Help coordinate clinically effective and cost-efficient programs for cancer care so that purchasers of insurance will have available products and coverage options with benefits for symptom management, palliative care/hospice programs, telemedicine, patient education, patient navigation, psychosocial support services, and care/survivorship plans
	Policy makers	Support hospice and palliative care programs that facilitate patient-centered care at the end of life
	Patients and families	Discuss end-of-life care issues with providers and family members as part of conversations surrounding treatment planning. Ask health care providers and systems of care for help and support

It is only through the efforts of policy-makers, health care providers, cancer survivors, and other cancer advocates that we will achieve the needed system changes to ensure that best-case care will be universally accessible to cancer patients and their loved ones.

The CQA invites advocates of quality cancer care to join its members in their efforts to overcome systems barriers through a cancer quality agenda. These scenarios well illustrate the critical need for action on policies to change health systems and promote quality care.

ABOUT THE CQA

The CQA was established in October 2005 as a forum for diverse stakeholders in the cancer

community whose mission is to improve the quality of care provided to people with cancer. The CQA is co-chaired by Patricia Ganz, MD, a medical oncologist and Chair of ASCO's Cancer Quality Committee, and Ellen Stovall, President and CEO of the National Coalition of Cancer Survivorship.

The CQA meets semiannually in Washington, DC. To learn more about CQA activities and how you can become involved, visit www.cancerqualityalliance.org or contact the representative of your professional or advocacy organization that is a member of the CQA.

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CQA Blueprint Glossary

Adjuvant therapy- Treatment given after the primary treatment to increase the chances of a cure. Adjuvant therapy may include chemotherapy, radiation therapy, hormone therapy, or biological therapy.

Advance practice nurse- Professionals qualified by education at an accredited school of nursing and licensed by state law to practice nursing. These individuals have a master's degree or higher. This category includes nurse administrators, nurse anesthetists, nurse clinical specialists, nurse practitioners, nurse psychotherapists, and nurse midwives.

Aromatase inhibitor- A drug that prevents the formation of estradiol, a female hormone, by interfering with an enzyme called aromatase that converts a by-product of cholesterol into a six carbon ring structure that then leads to the production of estrogen. Aromatase inhibitors are used as a type of anti-hormone therapy for postmenopausal women who have estrogen-receptor positive breast cancer.

Axilla- The underarm or armpit.

Axillary dissection- Surgery to remove lymph nodes found in the armpit region. Also called axillary lymph node dissection.

Balloon catheter- A flexible tube with a balloon at its tip, that can open narrow passages in the body, used to deliver fluids into or withdraw fluids from the body.

Bisphosphonate- A drug or substance used to treat hypercalcemia (abnormally high blood calcium) and bone pain caused by some types of cancer. Forms of bisphosphonates are also used to treat osteoporosis and for bone imaging. Bisphosphonates inhibit a type of bone cell that breaks down bone. Also called diphosphonate.

Bypass surgery- A surgical procedure in which the doctor creates a new pathway for the flow of body fluids.

Calcifications- Deposits of calcium in the tissues. Calcification in the breast can be seen on a mammogram, but cannot be detected by touch. There are two types of breast calcification, macrocalcification and microcalcification. Macrocalcifications are large deposits and are usually not related to cancer. Microcalcifications are specks of calcium that may be found in an area of rapidly dividing cells. Many microcalcifications clustered together may be a sign of cancer.

Carcinoma- Malignancy that originates in the skin or in tissues that line or cover internal organs such as the lung or liver, or tissues that arise from glands, such as breast carcinoma or pancreatic carcinoma .

Cardiac catheterization- a procedure using a flexible tube to deliver or withdraw fluids from the heart.

Clinical trials- Research studies that test how well new medical approaches work in people. These studies test new methods of screening, prevention, diagnosis, or treatment of a disease. Also called a clinical study.

Colostomy- An opening into the colon from the outside of the body. A colostomy provides a new path for waste material to leave the body after part of the colon has been removed.

Comprehensive cancer center-A designation of a cancer center by the National Cancer Institute (NCI) indicating the center's fulfillment of criteria related to research, prevention, care, education, information and dissemination activities that broadly serve communities, regions of the country, and often the nation.

Computer over-read-A physician review of a computer or machine generated medical scan.

Conventional radiation- A currently accepted and widely used treatment for cancer, based on the results of past research, that uses high-energy radiation from x-rays, gamma rays, neutrons, protons, and other sources to kill cancer cells and shrink or eliminate tumors.

Core biopsy- The removal of a tissue sample with a wide diameter needle for examination under a microscope.

CT scan- Computed tomography scan. A series of detailed pictures of areas inside the body taken from different angles; the pictures are created by a computer linked to an x-ray machine. Also called computed tomography scan, computerized tomography, computerized axial tomography scan, and CAT scan.

Dissection- surgical removal of tissue.

Dosimetry- Measurement of radiation exposure from x-rays, gamma rays, or other types of radiation used in the treatment or detection of diseases, including cancer.

Ductal carcinoma in situ (DCIS)- A noninvasive condition in which abnormal cells are found in the lining of a breast duct. The abnormal cells have not spread outside the duct to other tissues in the breast. In some cases, DCIS may become invasive cancer and spread to other tissues, although it is not known at this time how to predict which lesions will become invasive. Also called ductal carcinoma in situ and intraductal carcinoma.

Digital Video Disc (DVD)- A disc that can be used to view or store data in digital (electronic) format.

Electronic medical record (EMR) - A collection of a patient's medical information in a digital (electronic) form that can be viewed on a computer and easily shared by people taking care of the patient while still protecting the patient's privacy.

Estrogen receptor positive- Describes cells that have a protein to which the hormone estrogen will bind. Cancer cells that are estrogen receptor positive need estrogen to grow, and may stop growing when treated with drugs that block estrogen from binding or decrease estrogen levels in the body. Also called ER+.

Evidence-based guidelines-systematically developed statements, which provide assistance in medical decision making regarding specific clinical conditions. These statements are based on thorough evidence of clinical effectiveness and provide a standard of care for the reviewed condition.

Excisional biopsy- A surgical procedure in which an entire lump or suspicious volume is removed for diagnosis. The tissue is then examined under a microscope.

External beam radiation- A type of radiation therapy that uses a machine called a linear accelerator, or linac to aim high-energy rays at the cancer from outside of the body. Also called external radiation therapy.

Fraction of radiation-a small dose of radiation that is given daily over a specific time period to kill cancer cells and shrink tumors. This maximizes the destruction of cancer cells while minimizing the damage to healthy tissue.

Fractionation program-the series of radiation fractions to deliver the total dose of radiation to a tumor. The program describes the number of treatments, the dose pre treatment, the number of treatments per day (usually only one) and the number of days per week that the treatment will be delivered (usually four or five).-

Frozen section biopsy- The removal of cells or tissues for examination by a pathologist (a doctor who examines tissues and uses laboratory tests and microscopic analysis to make a diagnosis), who then freezes the tissue, cuts it into very thin slices, places it on a piece of glass called a "microscope slide," stains it with dyes, and then examines it under a microscope. This procedure can be performed during surgery to diagnose tissue quickly while the patient is still anesthetized in order to help the surgeon decide the appropriate procedure.

Guidelines- systematically developed statements, which provide assistance in medical decision making regarding specific clinical conditions.

Her2/neu- Human epidermal growth factor receptor 2. A protein involved in normal cell growth. It is found in high levels on some breast cancer cells. Also c-erbB-2.

Histology- The study of tissues and cells under a microscope.

HMO (health maintenance organization)- A type of insurance managed care plan where a group of doctors, hospitals, and other health care providers agree to give health care to HMO beneficiaries for a set amount of money from the insurer every month. The beneficiary usually must get care from the providers in the plan.

Hodgkin's Disease- A cancer of the immune system that is marked by the presence of a type of cell called the Reed-Sternberg cell. The two major types of Hodgkin disease are classical Hodgkin lymphoma and nodular lymphocyte-predominant Hodgkin lymphoma. Symptoms include the painless enlargement of lymph nodes, spleen, or other immune tissue. Other symptoms include fever, weight loss, fatigue, or night sweats. Also called Hodgkin lymphoma.

Hook-wire placement-a procedure using a needle-like device into a tumor to confirm its location prior to surgery.

Hormone replacement therapy- HRT. Hormones (estrogen, progesterone, or both) given to women after menopause to replace the hormones no longer produced by the ovaries. Also called HRT and menopausal hormone therapy.

Hypercholesterolemia-the presence of high levels of cholesterol in the blood.

Hypertension- A blood pressure of 140/90 or higher. Hypertension usually has no symptoms. It can harm the arteries and cause an increase in the risk of stroke, heart attack, kidney failure, and blindness. Also called high blood pressure.

Hypo-echoicity-tissue that only allows a small amount of echoes to bounce back during an ultrasound, compared to surrounding tissue. This could be a sign of a tumor.

Hypothyroidism- Too little thyroid hormone. Symptoms include weight gain, constipation, dry skin, and sensitivity to the cold. Also called underactive thyroid.

Limb-sparing- a surgical procedure designed to maintain the functionality of the arms or legs.

Local recurrence- Cancer that has recurred (come back) in its place of origin without evidence of spread, usually after a period of time during which the cancer could not be detected.

Localization- The process of determining or marking the location or site of a lesion or disease. May also refer to the process of keeping a lesion or disease in a specific location or site.

Lumpectomy- Surgery to remove the tumor and a small amount of normal tissue around it.

Lymph nodes- Rounded or elliptical collections of lymphatic tissue that are surrounded by a capsule of connective tissue. Lymph nodes filter lymph (lymphatic fluid), and they store lymphocytes (white blood cells involved in immunity). They are located along lymphatic vessels. Also called lymph glands.

Magnetic resonance imaging (MRI)- A procedure in which a powerful magnet linked to a computer induces radio waves in tissue that are used to create detailed pictures of areas inside the body. These pictures can show the difference between normal and diseased tissue. MRI sometimes makes better images of organs and soft tissue than other scanning techniques, such as computed tomography (CT) or x-ray. In addition, the MRI can also demonstrate abnormal functioning of the examined tissue, the degree of blood flow, or oxygen level of the examined tissue. MRI is especially useful for imaging the brain, the spine, the soft tissue of joints, the inside of bones, the liver, and the pelvic organs. Also called magnetic resonance imaging, nuclear magnetic resonance imaging, and NMRI.

Mammography- The use of low energy x-rays to create a picture of the breast.

Margins- The edge or border of the tissue removed in cancer surgery. The margin is described as negative or clean when the pathologist finds no cancer cells at the edge of the tissue, suggesting that all of the cancer has been removed. The margin is described as positive or involved when the pathologist finds cancer cells at the edge of the tissue, suggesting that all of the cancer may not have been removed.

Mastectomy- Surgery to remove the breast (or as much of the breast tissue as possible).

Medical oncologist-

A doctor who specializes in diagnosing and treating cancer using chemotherapy, hormonal therapy, and biological therapy. A medical oncologist often is the main health care provider for someone who has cancer. A medical oncologist also gives supportive care and may help coordinate treatment given by other specialists.

Multimodal treatment- Therapy that combines more than one method of treatment.

Needle biopsy- The removal of tissue or fluid with a needle for examination under a microscope. When a wide needle is used, the procedure is called a core biopsy. When a thin needle is used, the procedure is called a fine-needle aspiration biopsy.

Neoplasm- An abnormal mass of tissue that results when cells divide more than they should or do not die when they should. Neoplasms may be benign (not cancerous), or malignant (cancerous). Also called tumor.

Osteoporosis-

A condition that is marked by a decrease in bone mass and density, causing bones to become fragile.

Palliative care- Care given to improve the quality of life of patients who have a serious or life-threatening disease. The goal of palliative care is to prevent or treat as early as possible the symptoms of a disease, side effects caused by treatment of a disease, and psychological, social, and spiritual problems related to a disease or its treatment. Also called comfort care, supportive care, and symptom management.

Partial mastectomy- The removal of cancer as well as some of the breast tissue around the tumor and the lining over the chest muscles below the tumor. Sometimes some of the lymph nodes under the arm are also taken out and the procedure is called a partial mastectomy and axillary dissection. Also called segmental mastectomy.

Pathologist- A doctor who identifies diseases by studying cells and tissues under a microscope, and suggests laboratory tests to help determine the disease diagnosis.

Patient navigator- an individual who assists patients in finding various assistance services related to their medical care.

Positron emission tomography (PET)- PET scan. A procedure in which a small amount of radioactive glucose (sugar) is injected into a vein, and a scanner is used to make detailed, computerized pictures of areas inside the body where the glucose is used. Because cancer cells often use more glucose than normal cells, the pictures can be used to find cancer cells in the body. Also called PET scan.

Progesterone receptor- A protein found inside the cells of the female reproductive tissue, some other types of tissue, and some cancer cells. The hormone progesterone will bind to the receptors inside the cells and may cause the cells to grow. Also called PR.

Psychosocial- mental health related to one's social well-being.

Radiation oncologist- A doctor who specializes in using radiation to treat cancer. Like medical oncologists and surgical oncologists, radiation oncologists are specialists in understanding the behavior of tumors (their natural history), the risks of, and the locations of regions of spread, the tests to determine the extent of disease, and the various methods of treatment including but not limited to the various forms of radiation.

Randomized trials- scientific experiments to test the effectiveness of various medical treatments/procedures, using test subjects who either receive the experimental treatment

or the best standard treatment to ensure validity. These trials require prior evaluation by a body of physicians, ethicists, and lay people called an “Institutional Review Board,” to make sure that patients being offered treatment in the trial are protected against undue risk, explained the nature of the trial, and that their human rights are protected.

Rectal sphincter-A muscle in the rectum that closes the end of the rectum to prevent the inadvertent loss of fecal material.

Resection- A procedure that uses surgery to remove tissue or part or all of an organ.

Sacrum- The large, triangle-shaped bone in the lower spine that forms part of the pelvis. It is made of 5 fused bones of the spine.

Sarcoma- A cancer of the bone, cartilage, fat, muscle, blood vessels, or other connective or supportive tissue.

Sclerosing adenosis-a benign condition where non cancerous tissue grows within the breast lobules.

Sentinel lymphadenectomy- A surgical procedure in which the sentinel lymph nodes (the first lymph nodes in which cancer is likely to spread) are removed and examined to see whether they contain cancer.

Set-up appointment-a medical appointment that prepares a patient for some form of therapy.

Speculation- a hypothesis formed without hard evidence.

Staging work-up-a medical examination to determine the current state of a disease, based on its level of progression. This helps to initiate an appropriate treatment strategy.

Statin-Any of a group of drugs that lower the amount of cholesterol and certain fats in the blood. Statins inhibit a key enzyme that helps make cholesterol. Statin drugs are being studied in the prevention and treatment of cancer.

Stereotactic biopsies- Biopsy procedures that use a computer and a 3-dimensional scanning device to find a tumor site and guide the removal of tissue for examination under a microscope.

Survivorship- In cancer, survivorship covers the physical, psychosocial, and economic issues of cancer, from diagnosis until the end of life. It includes issues related to the ability to get health care and follow-up treatment, late effects of treatment, second cancers, and quality of life.

Survivorship care plan- A strategy for cancer survivors, developed in conjunction with healthcare providers, to manage post-cancer screening and the potential long-term effects of chemotherapy. This plan is used by the cancer survivor and his subsequent managing physician and care team to make sure that the appropriate follow-up care (after the active management of the tumor is completed) occurs.

Tamoxifen- A drug used to treat certain types of breast cancer in women and men. It is also used to prevent breast cancer in women who have had ductal carcinoma in situ (abnormal cells in the ducts of the breast) and are at a high risk of developing breast cancer. Tamoxifen is also being studied in the treatment of other types of cancer. It blocks the effects of the hormone estrogen in the breast. Tamoxifen is a type of antiestrogen. Also called tamoxifen citrate and Nolvadex.

Targeted [chemo]therapy- A type of treatment that uses drugs or other substances, such as monoclonal antibodies, to identify and bind to specific molecules and receptor on cancer cells resulting in their death without harming most normal cells.

Technetium-99 scan- a procedure using technetium-99 (a radioactive isotope) to detect tumor location, as organs containing cancer cells may take up technetium in higher concentrations than than normal cells. Examples of technetium scans include bone scans or radioactive breast scans.

Telemedicine- The delivery of healthcare from a distance using electronic information and technology such as computers, cameras, videoconferencing, the Internet, satellite, and wireless communications.

Tubular carcinoma- A type of breast cancer characterized by the invasion of the connective tissue framework of the breast by a cancerous growth of cells lining the breast (epithelial nodules). Tubular cancers are the form of breast cancer that is least likely to spread beyond the breast to the adjacent lymph nodes or other organs.

Tumor- An abnormal mass of tissue that results when cells divide more than they should or do not die when they should. Tumors may be benign (not cancerous), or malignant (cancerous). Also called neoplasm.

Ultrasound directed biopsy- A biopsy procedure that uses an ultrasound imaging device to find an abnormal area of tissue by bounding high frequency sound waves off of organs similar to the sonar that is used by submarines. Tumors tend to bounce the sound back to the imaging device differently than the surrounding normal tissue so as to guide its localization and removal for examination under a microscope.

Ultrasound localization- The process of determining or marking the location or site of a lesion or disease using high-energy sound waves (ultrasound), that are bounced off internal tissues or organs and make echoes. The echo patterns are shown on the screen of an ultrasound machine, forming a picture of body tissues called a sonogram.

Website URLs- Uniform Resource Locators (URLs) are groupings of text that direct your web browser to websites.

Well differentiated- a tumor that grows slowly, with a definite shape.