

Chapter 2

Models of Survivorship Care

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Chapter Overview The official definition of a cancer survivor encompasses those experiencing the entire trajectory of cancer care, including diagnosis, treatment, and beyond treatment. For each of these three phases, survivors have different health care needs. A report issued in 2005 by the Institute of Medicine, entitled “From Cancer Patient to Cancer Survivor: Lost in Transition,” brought to light the problems that many cancer survivors face once they are past the phase of cancer treatment. Survivors reported they struggled to find health care services and providers in their communities to address their persistent or late-emerging health problems that were secondary to their former cancer diagnosis or effects of treatment. This chapter will describe the process within our institution for developing a multidisciplinary care delivery model, as well as the components of care in the model. The domains of health care that address known and anticipated “after cancer” health care needs of survivors are as follows: surveillance for possible late recurrence of the primary cancer; screening and early detection, as well as prevention, of additional primary cancers; monitoring for and management of persistent or late effects of treatment; and psychosocial health. Communication between the primary oncology teams and community physicians is very important for continuity of care. It is recommended that a summary document be prepared as a care plan for each survivor, detailing the following: type of treatments received; residual and possible future late effects or complications; indicated evaluations for health maintenance; and cancer surveillance/screening.

Introduction: The Cancer Problem

The most current Surveillance Epidemiology and End Results (SEER) projections indicate high lifetime cancer risks for both men and women: 1 in 2 for men and 1 in 3 for women (Howlander et al. 2011). The malignancies for which both men and women are most at risk originate in organs influenced by sex hormones: prostate carcinoma is the most common cancer in men and breast cancer is the most common cancer in women (Table 2.1). The second most common malignancy is lung cancer, followed by colorectal cancer, in both men and women. These four malignancies (“the big four”) constitute the highest solid tumor burden in the US population. Among hematologic malignancies, lymphomas are the most common, ranking seventh in frequency for both men and women.

Why is cancer survivorship a big concern? Paradoxically, while the total number of cancer-related deaths has increased, so has the number of cancer survivors. A great deal of progress has been made in the treatment of malignant diseases. Among the big four cancers (prostate, breast, colorectal, and lung carcinomas), the only disease for which significant survival progress has not been made is carcinoma of the lung and bronchus. For the other three malignancies, 5-year survival rates have been increasing since the 1970s (Table 2.2; American Cancer Society 2012).

Table 2.1 Cancers occurring most often in men and women in the United States in 2012^a

Men (848,170 cases); cancer lifetime risk: 1 in 2		Women (790,740 cases); cancer lifetime risk: 1 in 3	
Cancer site	Percentage of cases	Cancer site	Percentage of cases
Prostate	29	Breast	29
Lung and bronchus	14	Lung and bronchus	14
Colon and rectum	9	Colon and rectum	9
Urinary bladder	7	Uterine corpus	6
Melanoma (skin)	5	Thyroid	5
Kidney and renal, pelvic	5	Melanoma (skin)	4
Non-Hodgkin lymphoma	4	Non-Hodgkin lymphoma	4
Leukemia	3	Kidney and renal, pelvic	3
Oral cavity	3	Ovary	3
Pancreas	3	Pancreas	3
All other sites	19	All other sites	23

Source: American Cancer Society (2012)

^aExcludes basal and squamous cell skin cancers and in situ carcinomas except urinary bladder**Table 2.2** Five-year relative overall survival rates^a (%) in the United States, 1975–2007

Site	1975–1977	1984–1986	1999–2007
All sites	50	54	68
Breast (women only)	75	79	90
Colon	52	59	66
Leukemia	35	42	55
Lung and bronchus	13	13	16
Melanoma	82	87	93
Non-Hodgkin lymphoma	48	53	69
Ovary	37	40	45
Pancreas	3	3	6
Prostate	69	76	100
Rectum	49	57	69
Urinary bladder	74	78	81

Source: Howlader et al. (2011)

^aBased on follow-up of patients through 2007

From Cancer Patient to Cancer Survivor

The SEER survival data show that among long-term cancer survivors (those living 5 years or longer beyond the date of their cancer diagnosis), 60% are older than 64 years and approximately 40% are in the working adult age bracket (20–64 years), or those in their productive years of life who are concerned about maintaining employment. It is projected that within the next 40 years the population of long-term cancer survivors aged 65 years or older will double compared with today's

numbers. This is very important because a higher frequency of concurrent illness occurs among survivors aged 65 years or older than among other age groups, and this can significantly influence both the management of cancer and the long-term complications of treatment. Therefore, managing the concurrent health problems of cancer patients and survivors is equally as important as managing the cancer itself.

Patients who reach long-term survivorship status can be well and reintegrate into a normal life. Unfortunately, many cancer survivors do not recover their health and do not receive adequate health care. The Institute of Medicine published a comprehensive assessment of the status of cancer survivors in the United States in 2005. This assessment noted that a significant proportion of survivors suffered from chronic, long-term physical, social, or emotional distress. The study, entitled *From Cancer Patient to Cancer Survivor: Lost in Transition*, found that a critical issue for many patients was limited access to health care and lack of coordination of their health care once the cancer treatment and intermediate surveillance was concluded (Hewitt et al. 2006). The study made several recommendations for health care providers, as well as for policy-makers and government bodies, to improve the care of survivors. A more recent updated report emphasizes ten additional recommendations (Levit et al. 2013). One of these recommendations is that care must be coordinated and integrate multidisciplinary expertise. At our own institution, we have developed a multidisciplinary care delivery model that incorporates the elements of care outlined in this chapter.

Surviving Cancer

The development of chemotherapeutic regimens as primary or adjunctive treatment for various cancers evolved rapidly in the 1960s and 1970s, as did the application and awareness of early cancer screening. In 1986, the founders of National Coalition for Cancer Survivorship set out to establish an organization that would change the phrase “cancer victim” to “cancer survivor.” To this end, the National Coalition for Cancer Survivorship crafted the definition of a survivor: from the time of diagnosis and for the balance of life. By the early 1990s, there was evidence of a sustained increase in the number of persons diagnosed with cancer who were living 5 years or longer beyond their diagnosis (Fig. 2.1). In 1996, the National Cancer Institute established an Office of Cancer Survivorship (OCS) in response to this trend, as well as in response to the concern that knowledge about the health of cancer survivors and the long-term effects of cancer treatment was significantly lacking. The OCS’s first challenge was answering the question: who is a cancer survivor? The OCS adapted the National Coalition for Cancer Survivorship’s definition of a survivor: “An individual is considered a cancer survivor from the time of diagnosis through the balance of his or her life” (National Cancer Institute 2012). OCS also expanded that definition to include the family and primary caregivers of the patient, because they all are influenced by the experience of cancer. Given the OCS’s very broad definition of who is a cancer survivor, when we speak of survivors’ health care needs we are speaking of a large and changing landscape; the cancer survivor’s journey today can cover a long chronologic trajectory.

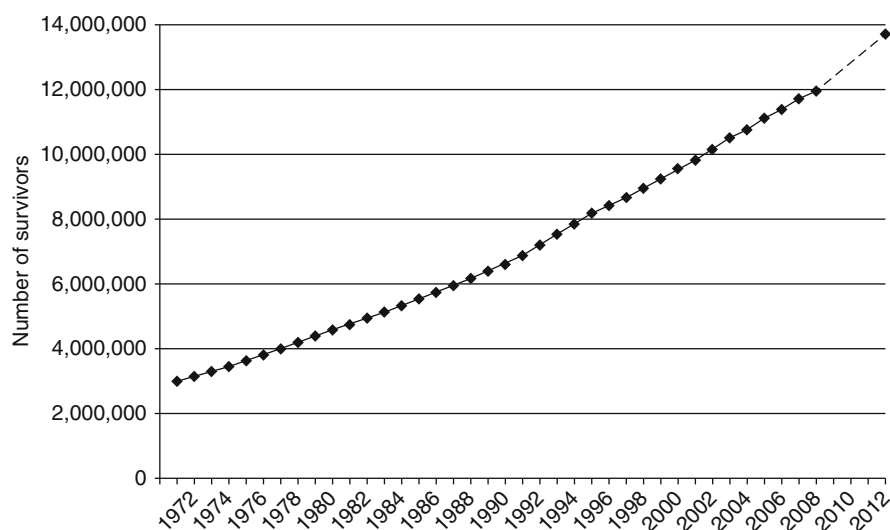


Fig. 2.1 Estimated number of cancer survivors in the United States between 1971 and 2012 (Source: American Cancer Society [2012](#))

Phases of Survivorship

The health care needs of cancer survivors, then, do not remain the same in later phases of survivorship as they were in the early phases of survivorship. The concept of “seasons of survival” was described in 1985 by Fitzhugh Mullan in an article in which he described his personal experience as a physician and a cancer survivor (Mullan [1985](#)). Dr. Mullan described three principally different cancer survival phases, distinct from each other both on an experiential level and from a clinical perspective.

The *acute phase* begins with the diagnosis of cancer and includes testing for and treatment of the malignancy. Clinical care at this point is principally oncologic (i.e., administered by surgical, radiation, and medical oncologists), with a focus on eradication of the malignancy and management of any acute complications of treatment. From the patient’s perspective, the primary experience is one of illness, treatment side effects, anxiety about the treatment, and fear of the cancer, as well as hope of reaching a remission.

The *intermediate phase* of survivorship begins upon reaching remission or concluding the primary treatment. This phase could include maintenance treatment or consolidation therapies for some patients. For example, in some stages of Hodgkin lymphoma, a primary treatment with chemotherapy could be followed by a course of radiation. Another example is breast cancer, which in many cases requires primary treatment with a combination of chemotherapy, radiation, and surgery, followed by hormonal maintenance for several years. In the intermediate phase of survivorship, the primary focus is watchful monitoring with examinations and appropriate studies to determine whether an early relapse will occur. Patients often experience anxiety and fear of recurrence, and recovery from the acute phase of treatment may be prolonged.

The *long-term phase* of survivorship, according to Dr. Mullan, begins when the period of highest risk for recurrence of the disease has passed and patients are considered well from that episode of cancer. The focus of clinical care in long-term survivorship should turn to maintenance of health, management of latent complications of the cancer treatment, reduction of risks of second malignancies, and cancer screening as appropriate. Since 1985, however, a new category of long-term survivorship has also emerged, in which patients live with chronic active cancer in a smoldering phase or with intermittent periods of remission broken by expected continual relapses that may need to be treated repeatedly. In today's reality, these patients are also long-term survivors. The goals of clinical care for these patients are the same as for cancer-free survivors, but in addition they must maintain very close surveillance and undergo intermittent treatment for their primary cancer as appropriate, repeating their trajectory through the earlier phases of survivorship at intermittent times.

Medical and psychosocial concerns therefore differ in each phase of survivorship, because patients' experiences and medical management objectives differ in each phase. The acute phase is obviously focused on effective cancer treatment and medical management of the side effects of the treatment, whether physical or psychological or both. In the intermediate phase, the principal concerns are monitoring for disease recurrence, allowing the patient to rehabilitate and recover from side effects, and managing fear and anxiety about recurrence. In the long-term phase, the main concerns are monitoring for long-term side effects of treatment and prevention and early diagnosis of possible subsequent malignancies. During the long-term phase, patients face issues of social and psychological health, reassessment of relationships, and spiritual and self-image crises. Equally important are pragmatic concerns about the economic consequences of survivorship. Employment discrimination is a reality for some cancer survivors, as is loss of health insurance. Cancer as a precondition excludes some patients from coverage or may exclude them from subsequent insurance coverage, especially if they change employment. These are serious and real concerns that will hopefully be addressed in the future by the newly formulated health care law.

The Uniqueness of Survivors

The most common cancer diagnoses among long-term survivors are breast, prostate, and colorectal cancer, followed by gynecologic malignancies and hematologic cancers. The groups of survivors affected by each of these diseases are distinct in terms of their medical care needs and the consequences of their treatment. These diseases require different therapeutic approaches: different possible surgical interventions, different possible radiation port sites and doses, and very different families of chemotherapeutic agents that in turn have different side effects. In addition, inherent biological differences within each of these malignancies may

influence the risk of late recurrences or other second malignancies. Lastly, the anticipated or potential side effects in both the short and the long term are unique to each initial presentation by stage and organ site within each disease category. Therefore, although some health concerns can be generalized to apply to all long-term survivors, each survivor's diagnosis and treatment combination results in specific long-term potential risks and complications.

Survivor Risk Stratification

We conducted a survey of the oncology specialists in our institution (surgical, radiation, and medical oncologists) and asked them to describe the health care services that their long-term survivor patients would need. The consensus was that, on the basis of the factors described above that make different groups unique, not all survivors need the same level of care because they are not all at the same risk of relapse or secondary consequences of their treatment. The 3-tiered model of risk stratification that was proposed is simple, based on broad treatment risk categories and inherent cancer recurrence risks.

Tier 1

These patients have a very low risk of complications from their treatment and a low risk of relapse. This category includes patients presenting with localized malignancies that may require only surgical resection that results in minimal secondary physiologic deformities, and these patients have a high probability of cure from that intervention (for example, patients with localized noninvasive colorectal adenocarcinomas that require only localized bowel resection).

Tier 2

This category includes patients whose malignancies must be treated intensively with multimodal therapy to achieve a favorable outcome. These patients are often exposed to radiation or chemotherapy in addition to surgery. They may experience significant organ- or system-specific complications during treatment or may be at risk for second late malignancies, latent specific organ dysfunction, or other unknown consequences that may remain a concern for the rest of their lives. Tier 2 patients constitute a large group of individuals (the majority of the long-term survivors at our institution, for example, are in this risk group).

Tier 3

Patients in this category have a malignancy with a high risk of relapse or have chronic cancer. They may have active indolent or controlled disease or they may undergo dose-intense treatment, such as a stem cell transplantation or other uniquely toxic therapy, that has known or expected long-term active secondary negative effects.

Stratification of Health Care Needs on the Basis of Risk

The components of health care needed by persons who have survived cancer are therefore quite varied in their complexity, cutting across various specialties and encompassing several domains. The primary concern for survivors when they have their yearly examination is whether their primary cancer has recurred. This requires surveillance studies and careful physical examination. Secondly, survivors are at risk for and fear developing other cancers. Early cancer screening, as appropriate for their age, prior diagnoses, and other risk factors, is therefore a second important component of their care. An additional health care need is cancer prevention and counseling for lifestyle changes to prevent cancer, as well as risk assessment in certain populations for whom genetic counseling may be appropriate. Side effect management, including health maintenance and observation of vital organ function, is important particularly for those who may have already suffered from toxic effects in vital organs or are vulnerable to specific latent toxicities related to the treatment they received. Lastly, quality of life and social health issues are important to address to help the patients maintain healthy relationships with their families, communities, and employers, and to help restore functionality in their lives.

However, the categories of medical care and psychosocial support services that long-term survivors may need can also be stratified by the risk categories noted above. The continuum of multidisciplinary care according to risk tiers is diagrammed in Fig. 2.2 and can be summarized as follows.

Tier 1 Patients

Care should focus on cancer prevention and, when appropriate, psychosocial support. Patients may be anxious about the possibility of getting a second cancer, which can be addressed by encouragement to maintain a healthy lifestyle and conscientiously follow the recommended cancer screening guidelines.

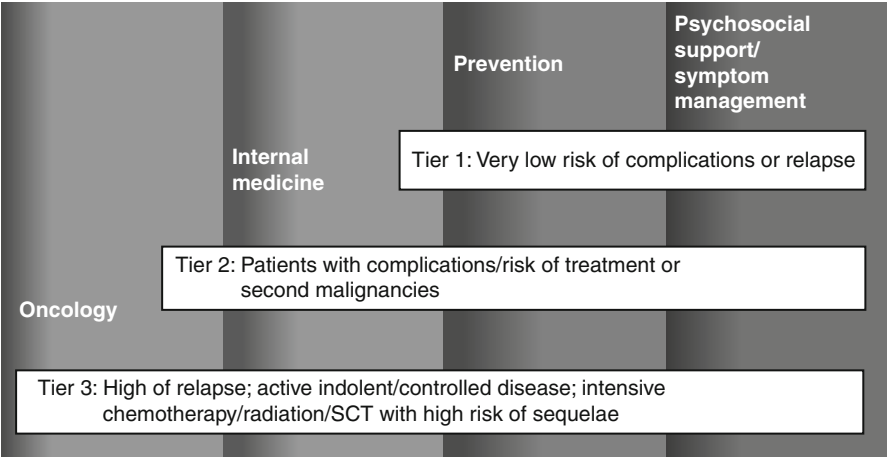


Fig. 2.2 Continuum of care for each risk tier (*SCT* indicates stem cell transplantation)

Tier 2 Patients

Patients may require support across the full spectrum of health care, including psychosocial support, if they suffer from chronic fatigue or ongoing organ dysfunction secondary to treatment toxicity. These patients may also require support from internists or other specialists for treatment-related late or persistent side effects; cancer prevention and screening; management of comorbid conditions to ameliorate risks of organ dysfunction; and, in many cases, ongoing oncologic surveillance because of the long-term risk of secondary malignancies.

Tier 3 Patients

For the rest of their lives, patients in this category need to be monitored for recurrence or new malignancies, as well as for persistent or latent consequences of the treatment itself. These patients remain under the care of their oncologist but also require the care of an internist to monitor their overall health and manage complications. In addition, cancer prevention, secondary cancer screening, and psychosocial support remain important and necessary throughout the rest of their lives.

A Model of Multidisciplinary Oncology

In 1997, a new model was implemented across all of the ambulatory clinics at MD Anderson, intended to deliver on-site, real-time multidisciplinary care. A key principle of the multidisciplinary care centers (MCCs) is that they are patient-centered, tailored to the patient's specific illness. A team approach to patient care is used, with on-site participation by all key oncology specialists (surgical, radiation, and medical oncologists), and a partnership is formed within the team from different levels of providers, including physicians, mid-level providers, nurses, trainees, and administrative support staff. These individuals are all integral members of the patient's primary team (Fig. 2.3). Treatment planning integrates the recommendations of each of the essential treatment specialist groups. Furthermore, decisions are made at the point of service, as the patient comes to the clinic.

There are several benefits with this care delivery system. First, expertise encompassing all of the major oncologic specialties is focused around a specific disease or disease category. Second, having all specialists centrally located in one site decreases the time and energy that patients previously spent coordinating appointments in various centers. Third, timely on-site interaction, discussion, and planning of care among the clinicians can expedite the initiation of appropriate therapy. The proximity of all of the necessary specialists also facilitates collaboration in clinical research protocols across the specialties. Finally, the patients have a "home" they identify as their resource base.

Each MCC also integrates care from specialists in supportive care disciplines, such as social services, patient advocacy, and nutrition. In addition, MCCs have access to and coordinate consultations as needed with specialists in areas that reside outside of the MCC's disease focus, such as physical medicine and rehabilitation and diagnostic services. Within each of these MCCs, we integrate not only clinical service, but also research programs, both clinical and translational, that require the coordination and participation of specialists in multiple disciplines. In addition,

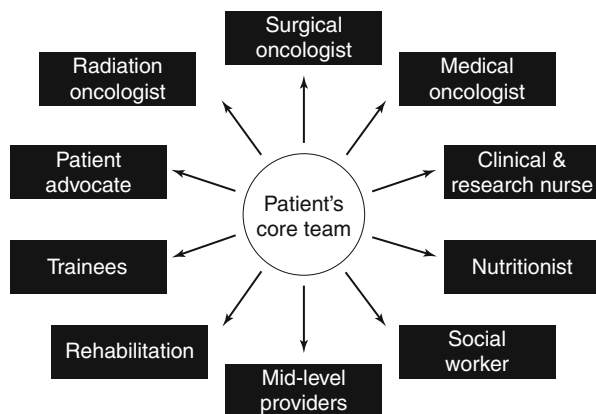


Fig. 2.3 Multidisciplinary care center model used at MD Anderson

medical fellows, residents, and other clinical trainees such as physician assistant students and residents rotate through the MCCs to learn about the management of specific malignant disorders in that setting. Hence, this model also serves as a focused experience and teaching resource for clinical trainees.

The MCC model encompasses multiple levels of service and patient care objectives. It has served very well, in our experience, to meet the needs of cancer care planning during the acute and intermediate phases of survivorship. We have applied this model across all of the major malignancy categories. For example, the oncologic care of all patients with breast cancer resides in one location, the Nellie B. Connally Breast Center. Similarly, the Leukemia Center has a specific disease focus, and all patients undergoing treatment for leukemia are cared for in this center.

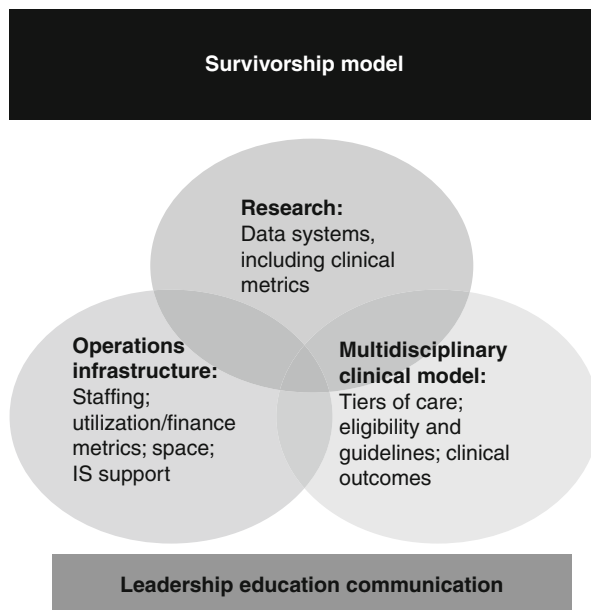
Given the success of the MCC model for care delivery during the first two stages of survivorship, we have chosen to extend the application of this model into long-term survivorship. However, the unique clinical needs of long-term survivors are not necessarily focused on oncologic care, but rather on reintegration to wellness. The patient's clinical team therefore changes from principal oncologic specialists (surgeons, radiation oncologists, and medical oncologists) to specialists in cancer prevention, psychosocial issues, and internal medicine, with the continued engagement of oncologists as appropriate depending on the risk tier level of the patient.

Multidisciplinary Survivorship Care

We have launched a pilot program (Fig. 2.4), similar to the MCCs, to test models of multidisciplinary long-term survivor care, which are specific to each malignancy. We designed a process road map to define the scope of the project and defined basic core principles of the project.

The first principle is that survivorship requires tiers of care based on the tiered-risk model described above. The second principle is that the amount of time between diagnosis and long-term survivor status varies by disease type, risk of recurrence, treatment duration, and surveillance guidelines. Although we acknowledge that the endpoint of 5 years of survival beyond the cancer diagnosis (used in the SEER database) is very valid, some patients may be appropriately transitioned to the long-term survivor clinic in less than 5 years if their risk of recurrence is low. Determination of the tiers of care and appropriate time to transition to long-term survivor care for each disease must be defined by the disease experts (i.e., the clinicians in each MCC) who are most qualified to identify the risk factors that are relevant to the disease they treat. A third principle is that an adequate infrastructure to deliver care must be provided, and this needs to be based on metrics to better understand practical logistic limitations and the populations being served. Lastly, a fourth key principle is that the integration of research into the framework of long-term survivor care is as important for survivorship care as it is for acute cancer care.

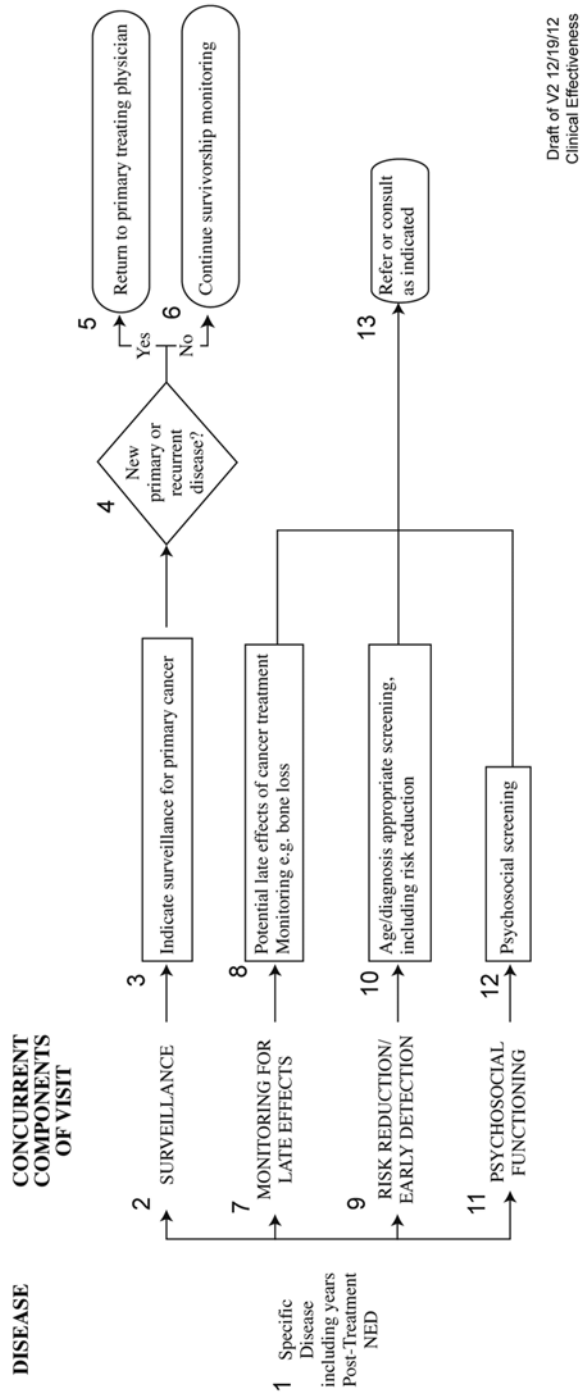
Fig. 2.4 Important aspects of the multidisciplinary survivorship care model used at MD Anderson (*IS* indicates information services)



Process of Team Development

The process of developing each pilot clinic began with engagement of the clinical leadership of each MCC. A steering team was formed that included leaders from the corresponding MCC, and these steering teams led the clinical development process. Each steering team first defined criteria of eligibility for patients to transition to the long-term survivorship clinic. To assist the clinicians in this process, we performed an extensive literature review of late effects specific to that disease and its treatment, so that final recommendations were evidence-based as much as possible. The recommendations for care were outlined in clinical practice algorithms, which were standardized across all diseases to address four key domains or categories of care: (1) surveillance of the primary malignancy, (2) cancer prevention and early screening, (3) management of secondary effects of treatment, and (4) psychosocial functioning. For each disease category, however, the content within these domains varied as appropriate to that disease. The algorithm framework is illustrated in Fig. 2.5. The algorithms that appear at the end of the chapters throughout this book follow this general framework.

Each team identified its own multidisciplinary partners. For example, in the pilot Gynecologic Oncology Survivorship Clinic, sex counselors and bone health experts were deemed necessary team members. The multidisciplinary partners then worked together to design the practice algorithms and a transitional plan to address health care needs (which we called a “passport”; see below), as well as patient educational materials relevant to their own disease discipline. Although these processes occurred



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Fig. 2.5 Survivorship clinical practice algorithm standardized template (algorithms for specific malignancies are available online; see Suggested Readings)

in tandem, or in close sequence, a significant amount of time and dedicated support staff was required to help the team stay on task and moving toward the goal and to maintain engagement of the clinicians.

Patients' Point of View

We received support for the overall concept of multidisciplinary care from patients through a series of surveys and focus groups conducted at the beginning of the process. Patients stated that they wanted to have their oncologists direct their survivorship care. However, if the patients' oncologists considered them well enough to go to the survivorship clinic, they were willing to be transitioned to other providers as long as this care remained close to the oncologist or was in some way linked to the primary MCC. The patients did not want the oncologists to lose track of information pertinent to their care.

Patients also told us that they were delighted to have a single place to go to address their side effects of treatment and cancer surveillance and early detection tests at the same time, because many of them did not have adequate and consistent cancer screening and testing available in their communities. Patients who lived far from our institution (defined as those living more than approximately 200 miles away) told us they still wanted us to direct their long-term survivorship care by advising their community physicians about appropriate follow-up evaluations. This feedback aligned with our design of the "passport" document.

Passport Plan for Health

Some patients stated that they would feel abandoned if they were denied long-term follow-up at our facility, whereas others felt that the burden of travel was too much for them to continue coming to our institution for life. Physicians in the community told us that they also feel frustrated if they cannot get timely support or advice on management of patients who have survived cancer. Addressing the expectations of both the patients and the primary care providers is therefore a challenge, and we acknowledged the need to create possible solutions to the problem as the population of survivors grows larger. The Passport Plan for Health document was designed to be one such solution (Fig. 2.6). It is a summary of each individual patient's cancer treatment history, and it includes known and anticipated complications that the patient might experience. The document is HIPAA compliant; patients and their primary care physicians at this time can access this information through a password-protected website.

The Passport Plan for Health also lists for the community physician recommendations for testing and possible consultations that we consider indicated.

THE UNIVERSITY OF TEXAS
MD Anderson
Cancer Center

Passport Plan for Health: Breast Cancer

Healthcare Provider: _____

Allergies: _____

Cancer Diagnosis: _____ Stage: Left Breast: _____ Right Breast: _____

Histology - Left: _____ Right: _____

Estrogen Receptor: _____ Progesterone Receptor: _____ Her2/neu: _____

Positive genetic findings: _____

Additional Cancer Diagnosis _____

Past medical history: _____

CANCER TREATMENT HISTORY:

Surgery ☐ Yes (indicate date, site and procedure) ☐ No

Procedure _____

Site _____

Final breast surgery: _____

Final axillary surgery: _____

Breast reconstruction: _____

Other: _____

Chemotherapy ☐ Yes (indicate date, site and procedure) ☐ No

Drug Name _____

Cycles/Year _____

Current Medication _____

Completed _____

Year _____

Radiation Therapy ☐ Yes (indicate date, site and procedure) ☐ No

Side _____

Site _____

Total Dose _____

Number of Fractions _____

Date Printed: _____ MRN: _____

Pt Name: _____

Fig. 2.6 Passport Plan for Health document template

THE UNIVERSITY OF TEXAS
MD Anderson
Cancer Center

Passport Plan for Health: Breast Cancer

Allergies: _____

Late Effects of Treatment/Signs and Symptoms to Report

Active ☐ Potential ☐ Recommended Consults/Monitoring _____

Recommended surveillance/prevention

Diagnostic Tests / Procedures Last Performed Year Location

Bone Density (Osteoporosis) _____

Gyn Cervical Screening _____

Colonoscopy _____

Breast Exam; Mammogram _____

Skin Exam _____

Genetic Counseling _____

General Preventive Health Care and Personal Health Behaviors Recommendations

General Recommendations _____

See primary care provider at least once a year _____

Maintain adult vaccinations (per CDC recommendations) _____

Maintain a healthy weight through diet and exercise _____

Maintain a tobacco-free lifestyle _____

Limit alcohol intake _____

Use sunscreen and limit time spent in sun _____

If addressed, seek support resources _____

Review patient education handouts _____

Other Instructions/Information:

For questions regarding this patient's care, please notify: _____

Signature/Credentials/ID Code: _____ Telephone: _____ Fax: _____

Counseled Recommendations

Future Date/Location

Year _____

Location _____

Recommendations must be tailored to the patient's specific malignancy and treatment, including the risk tier. For tier 1 patients, prevention and cancer screening care can usually be done most conveniently in the patient's community. For tier 2 patients, on the other hand, we generally recommend continued follow-up at our institution, if at all possible, for monitoring the late consequences of treatment. If this is not feasible, the primary care physician can be advised on the appropriate monitoring indicated. Tier 3 patients, on the other hand, must continue to be monitored in our clinics.

Value in Care Delivery

Looming large in our future is health care reform, which purports to follow principles of value-based health care delivery. The concept of value-based health care delivery has been postulated by Michael Porter and Elizabeth Teisburg in their book, *Redefining Health Care: Creating Value-based Competition on Results* (2006). The premise is that compensation for health care is currently based on quantity (of tests or exams) but should be based on the value derived by the patients. Porter and Teisburg define value as health *outcomes* divided by the *cost* of delivering care. Hence if the outcomes of care delivery by system "A" are superior to those of system "B" but the costs are the same in both systems, then the value of system "A" is higher. Porter and Teisburg propose that to maximize value, care delivery must be organized around medical conditions. Medical conditions in turn are defined as interrelated circumstances that must be addressed in an integrated way by multiple specialists and units of service. Systems of care are designed to include all units that address the full cycle of that medical condition. This is intended to optimize the use of expertise for that medical condition in a timely and efficient process. Cancer is an example of a medical condition with a long cycle of care, from early detection to long-term survival.

The value-based model also identifies a *hierarchy of health care outcomes*, with the most important (first tier) outcomes being survival and recovery. In cancer care, recovery equates to complete remission. The second tier in the hierarchy of outcomes as it relates to cancer is time to recovery or return to normal activities, and the third tier is sustainability of health. In cancer care, we and others have focused on diagnosis, treatment, and surveillance for recurrence, and these three steps have always been the key delivery elements in the care models that we have built. However, we must acknowledge that beyond these steps lies long-term survivorship, and that patients will face other health problems besides cancer recurrence, including latent side effects of treatment and exacerbation of other health conditions. Sustainability of health is very important for the patients who have survived the acute treatment of their cancer and remain free of their primary cancer.

Survivorship Research

Research should also be an integral part of the cycle of cancer care delivery; research should optimize the efficiency of research efforts and serve all levels of the cancer cycle: prevention and early detection, treatment, surveillance, and survivorship. Epidemiology, genetics, molecular genetics, and clinical studies on treatment-related morbidities and the impact of comorbidities on outcomes are all important research topics that are relevant from cancer diagnosis to long-term survivorship (Fig. 2.7).

Because many curative strategies have been developed for childhood malignancies, the concept of monitoring pediatric cancer survivors for the long term has been in existence for several decades. As a result, there is a significant body of data on the long-term outcomes of childhood cancer therapies, and these data have led to significant changes in the treatment intervention phase of the cancer care cycle. For example, treatment protocols for childhood lymphoma and leukemia have evolved significantly toward elimination of radiation to prevent cognitive and neurologic developmental toxic effects, as well as musculoskeletal developmental toxic effects. Treatment regimens also have been progressively altered to prevent other late effects of treatment that influence normalcy and quality of life, such as sterility. A great deal of research has been done regarding fertility preservation or conservation

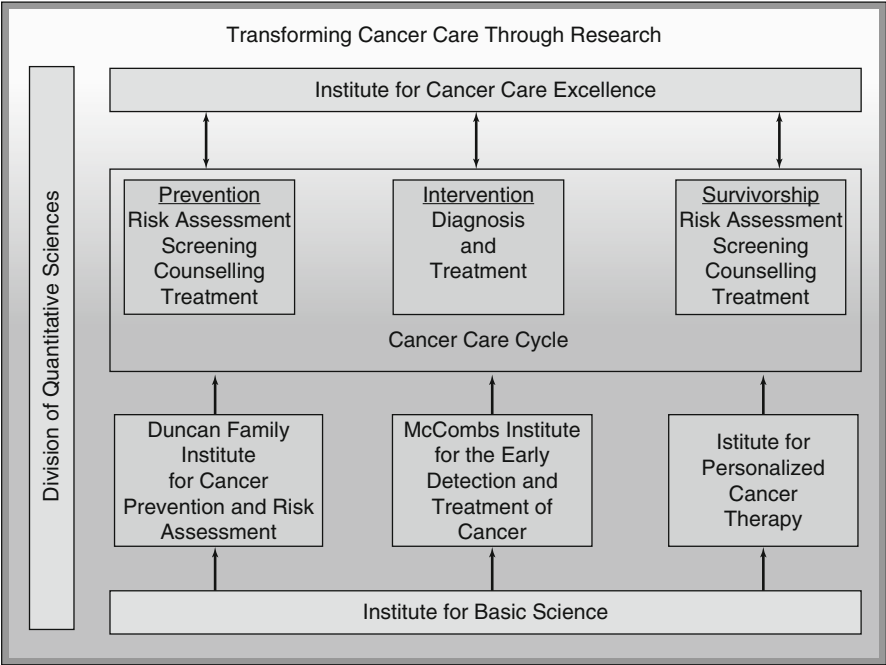


Fig. 2.7 Cancer research focus at MD Anderson

in pediatric cancer patients (Lee et al. 2006). More recently, attention has been focused on the early detection and prevention of breast cancer in girls and young women treated with radiation to the mediastinum, as well as the use of magnetic resonance imaging as a surveillance tool rather than standard mammography for secondary breast cancers (Aisenburg et al. 1997). Hence, significant changes have been made to the treatment strategies for childhood cancer as a consequence of long-term survivorship research. The same level of focus on long-term survivorship outcomes in adults has not yet taken place, but we hope to change that.

Key Practice Points

- Both cancer survivors whose highest risk of cancer recurrence has passed and those living with chronic active disease are considered to be in the long-term survivorship phase.
- Survivors' needs vary in terms of medical care and consequences of their treatment depending on the malignancy they have survived.
- The multidisciplinary care model is an effective way to meet the needs of cancer care planning for patients who have entered the long-term phase of survivorship.
- The essential components of care in the long-term phase of survivorship are surveillance of the primary malignancy, management of latent complications of cancer treatment, reduction of risks for second malignancies (including cancer screening), assessment of psychosocial functioning, and coordination of care with the survivor's community providers to ensure that all of the survivor's health needs are addressed.
- Systematically developed evidence-based clinical practice algorithms serve as an important tool to identify and manage late effects of cancer and its treatment and can be accessed at the following site: <http://www.mdanderson.org/education-and-research/resources-for-professionals/clinical-tools-and-resources/practice-algorithms/index.html>.
- The Passport Plan for Health survivorship care plan follows the recommendations of the clinical practice algorithms, informing both the survivor and clinicians involved in the care of the survivor about potential or actual latent treatment effects, signs and symptoms to report and recommended follow-up plans for surveillance, and cancer screening and health promotion.

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