60 Years of Survival Outcomes at The University of Texas MD Anderson Cancer Center

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Chapter 1
Introduction

M. Alma Rodriguez

The University of Texas MD Anderson Cancer Center, which began operations in 1944, was designated one of the first three comprehensive cancer centers in 1971 under the National Cancer Act and has kept that designation ever since. The first leader of the institution, Dr. Randolph Lee Clark, was a visionary who, from the onset of planning the institution, understood the importance of having an integral record of the many cancer patients treated at the institution and of their survival outcomes. He therefore included, as part of the institution's operational plan, a tumor registry that since 1944 has continuously captured the story of the treatment and outcome of every patient who has walked through the doors of the institution. This uninterrupted data repository, unique in its consistency throughout the institution's history, permits us to retrospectively analyze the changes in survival outcome made within the setting of our cancer-specific care-delivery system over the past 60 years. This monograph is the result of a retrospective review of our Tumor Registry data across six decades and presents a snapshot of the parallel history of cancer care at the institution.

As you will see, survival outcomes, in general, have significantly improved for cancer patients across nearly all disease sites during those 60 years. In some disease categories, this change has been dramatic even for disseminated stages of the disease, whereas in others, such as lung cancer, relatively a little has changed over the course of more than half a century. In the major solid tumors, such as breast and prostate cancers, as well as in gastrointestinal malignancies, very significant

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improvements in outcome have been seen for locally invasive presentations. These improvements can be attributed to multiple factors, but we believe a key element is our disease-based model of care, which integrates multidisciplinary planning and management focused on each specific cancer. Hence, the significant improvements in breast malignancies, for example, can be attributed to concurrent application and improvements in multiple disciplines: progressively better and more accurate diagnostic imaging tools, increasingly effective adjuvant chemotherapy, progressively refined surgical interventions, and progressively advancing radiotherapeutic technologies. All of these modalities and processes have been integrated into algorithms of care for each disease category and are updated as new evidence arises that requires change in disease management. A sample algorithm is illustrated in Fig. 1.1.

Another very important and critical part of the care-delivery design at MD Anderson has been the inclusion of clinical research. Applying the advances made in research to the bedside care of patients, a process summarized in this monograph, has been a driving force at our institution. In situations where clinical investigation is a priority, our clinical care algorithms integrate this recommendation.

The improvements made in cancer outcome across six decades have been incremental and stepwise and do not rely on any single strategy. These improvements have been achieved by integrating the efforts of multiple disciplines. Furthermore, increasing public awareness of the importance of cancer screening and making these screening methods more readily accessible have led to the detection and management of cancer at earlier stages, which can make an enormous difference in terms of survival outcome.

The Tumor Registry is not just a history of cancer care at MD Anderson. It has been a cornerstone for outcomes research and has been instrumental to our clinicians publishing many articles that have influenced cancer care practices. We believe that the Tumor Registry will lead to even bigger contributions to cancer care as information technologies develop. The continually evolving electronic medical records technologies, we hope, will lead to structured documents that standardize clinical terminology and data capture. This would result in more consistent information that would be comparable not only within but across institutions. Furthermore, it is critical to have centralized data that continuously and consistently capture meaningful clinical outcomes. Tumor registries in the future should be increasingly integrated with medical records to ensure more timely and complete data capture.

The value of any care-delivery system is ultimately defined by incremental improvements and consistently sustained good results. We believe that health care delivery that focuses on a group of diseases, self-reflects, self-corrects, and integrates research in all aspects of the management of illness, in a continuum and with consistency, can result in sustained outcome improvement.

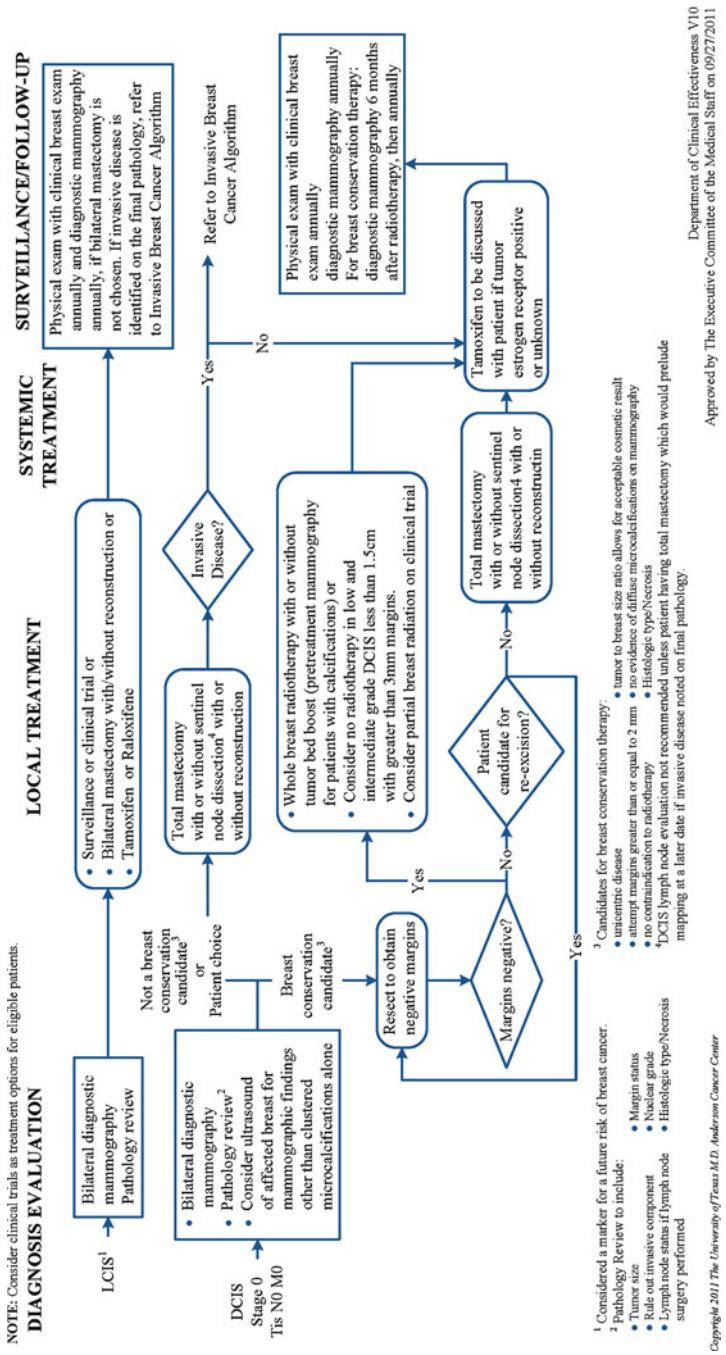

Fig. 1.1 Sample algorithm. Used with permission from MD Anderson Cancer Center.

Chapter 2
History of MD Anderson's Tumor Registry

Sarah H. Taylor

The Tumor Registry Department at The University of Texas MD Anderson Cancer Center is responsible for a database that contains demographic and disease information for all patients assigned a medical record number at MD Anderson, starting with the first patient registered on March 1, 1944. In its function as a hospital registry, the Tumor Registry database contains information about every patient seen at the institution, regardless of the patient's final diagnosis. The institution has always focused on cancer, and every patient has come to the institution because of a cancer-related issue: some with a malignancy, some with a benign or nonneoplastic condition, and some to rule out cancer. Because of this, each patient's information is of value to the hospital.

The institution, originally named the Texas State Cancer Hospital and the Division of Cancer Research in 1941 and then renamed to MD Anderson Hospital for Cancer Research of The University of Texas in 1942, had two purposes from its beginning—to conduct cancer research and to provide care for cancer patients. The registry database was initially established in September 1948 and was housed in the Department of Epidemiology. Eleanor Macdonald was appointed as Professor of Epidemiology and department head.

Miss Macdonald is known as the first cancer epidemiologist. Before coming to MD Anderson, she worked for the Massachusetts Department of Public Health, where she was the first to precisely determine incidence rates for cancer, and for the Connecticut State Health Department, where she developed the first population-based cancer registry and conducted the first vital status follow-up for cancer patients [1].

By the time Miss Macdonald arrived at MD Anderson in 1948, a total of 2,857 patients had come to the hospital. Under Miss Macdonald's leadership, a

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multifunctional department was established, and its responsibilities included abstraction of data, patient vital status follow-up, epidemiological research, and consultative services for basic and clinical researchers ([2], p. 41). In this new department, Dr. R. Lee Clark, MD Anderson's first president, established a section of information and statistics. Miss Macdonald developed a code of 200 pertinent items applicable to each patient that were designed in anticipation of requests for information for administrative, clinical, and research areas ([2], p. 107). The department also developed and maintained an IBM data processing unit to facilitate access and use of data. Information was stored on punch cards for each case and then stored in indices for "easy recall" ([2], p. 198). This processor made possible constant evaluations as well as monthly and annual assessments.

The handbook for tumor clinic secretaries that Miss Macdonald developed in 1956 at MD Anderson was an outgrowth of one used to train workers at the Connecticut State Health Department. That handbook was eventually sent to every hospital in Texas. At the request of the American College of Surgeons (ACoS), the handbook was also sent to every general hospital in the United States and Canada. The handbook was designed to enable workers without any other source of instruction to build a hospital cancer registry and follow-up service that would fulfill the requirements of the ACoS ([2], p. 315).

Miss Macdonald stepped down as head of the department in 1974. When Vincent Guinee, M.D., who had been an epidemiologist for the City of New York Health Department, became the department head in 1976, the database contained information on more than 112,000 patients. Under Dr. Guinee, the department, which changed its name to Patient Studies, continued to collect a well-defined and consistent data set on each patient and to assist researchers within the institution.

In 1979, the 66th Legislature enacted the Texas Cancer Control Act (House Bill 853), which created the Cancer Registry Program within the Texas Department of Health, making cancer a reportable disease [3]. Because of this need to have submittable data and to facilitate internal data retrievals, Dr. Guinee had the registry data moved to a mainframe NOMAD database.

Under the guidance of Dr. Guinee and at the direction of Dr. Clark, MD Anderson founded the International Cancer Patient Data Exchange System, which was funded by the International Union Against Cancer (UICC). Under this system, data from the registries at MD Anderson, Roswell Park Cancer Institute, Memorial Sloan-Kettering Cancer Center, and 11 other institutions in 10 other countries were compiled into one massive database. With this large number of patients, collaborative studies of rare cancers were carried out.

Dr. Guinee was head of the Department of Patient Studies until 1994. When he left, the database had grown to include more than 315,000 patients.

Since 1995, the department has been under the Office of the Physician-in-Chief. That year, the mainframe database was converted to 4th Dimension (4D), where it still resides. The customized in-house software makes possible the continuation of consistency in the collection of data over the span of the institution and makes possible inclusion of past histories of cancer and nonmalignant diagnoses that were originally thought to be cancer. The software also allows retension and expansion of

query tools that were initially developed on the mainframe. These query tools are essential for the extensive institutional use of the data for research and administrative purposes. As of December 31, 2011, the database contained information on more than 850,000 patients.

Registry Operations

Information is collected for all malignancies over the life of the patient, benign neoplasms seen at MD Anderson, and nonneoplastic conditions that affect the patient's cancer treatment or constitute the only diagnosis for the patient.

The MD Anderson Tumor Registry staff provide annual vital status follow-up of patients who currently have or had malignant disease, including foreign patients and patients not definitively treated at MD Anderson. This comprehensive follow-up structure provides the fundamental outcomes information necessary to conduct research on a broad spectrum of clinical research topics.

Responsibilities of the Coding Section

The Coding Section of the Tumor Registry is responsible for abstracting demographic and disease information for all patients registered at MD Anderson. The following describes the specific activities of the Coding Section.

Identification and Processing of New Patient Information

On the sixth day of each month, the Coding Section manager downloads a file of all medical records assigned to new patients during the previous month. Patients' demographic information captured during registration is also downloaded. The medical record numbers and demographic data are read into the 4D database, the transactional database used by the Tumor Registry. This read-in process includes several edits. Designated coders are responsible for resolving errors in the data and assigning codes for each patient's referral diagnosis. Certain errors are reported back to the Referral Office so the correction can be made to the institution's system. Once demographic information has been processed, it becomes part of the available Tumor Registry data and awaits abstracting of disease information by the coding staff.

New Patient Abstracting

The Coding Section of the Tumor Registry is responsible for abstracting information from the charts (either electronic or paper) of each patient who registers at MD Anderson. Abstracting is done no sooner than 4 months after a patient registers.

This allows adequate time to elapse for the charts to contain definitive staging information and final pathology reports and for the first course of therapy (defined as therapy given during the first 4 months after registration) to be completed at MD Anderson. Completion of coding of data for newly registered patients from any given month usually takes 2 months. Categories of data abstracted include additional demographic information, malignant neoplasm information (including site, histology, stage, treatment before admission to MD Anderson, treatment at MD Anderson, and sites of metastases), benign neoplasm information (including site, histology, treatment before admission to MD Anderson, and treatment at MD Anderson), and pertinent nonneoplastic conditions and follow-up information (including vital status, date of last contact/death, method of follow-up). The staff of 13 abstracters recorded information for approximately 44,000 new patients during 2011.

Once new patient abstracting is completed for a given month, the disease information becomes available for data retrievals by department staff and is also available to hospital staff from Clinic Station and the institution's data warehouse.

Reabstracting After Notification of Death

The Follow-up Section of the Tumor Registry identifies patients who have died (see Responsibilities of the Follow-up Section) and provides that information to the Coding Section. The Follow-up Section is currently verifying approximately 10,000 patient deaths per year. The Coding Section is responsible for recoding the charts of these patients. At this final death coding, any new cancers, treatments, or metastases that occurred since the last coding (usually the coding that was done 4 months after registration) are abstracted, and the vital status and death information are updated in the database.

Second Primaries

Once a month, the Pathology Department provides the Tumor Registry Department with a file of all pathology reports from the previous month. The Coding Section uses this file to identify living patients with primaries that developed after initial coding. The file of more than 8,000 pathology report codes is reduced electronically to about 300 possible new cancers. A review by the abstracting staff of each of these 300 reports results in about 100 new cancers per month being coded and added to the database.

Quality Assurance of Coded Data

Once data have been abstracted from a chart, they are "saved," at which point the computer edit program is run. Any errors detected by the edit program are corrected by the coder. The coder then gives the chart to another coder who accesses the

checking screen to verify site, histology, and stage. Through this process, the coders are able to provide visual verification of the site, histology, and stage for 100% of the charts abstracted. In more difficult cases, the manager of the Coding Section contacts physicians to ensure that the most accurate information is abstracted. In addition, feedback from data users is used to enhance data quality.

Responsibilities of the Follow-Up Section

The Follow-up Section is responsible for obtaining the vital status of every MD Anderson patient with a diagnosis of cancer on an annual basis. During 2011, last contact information was updated for almost 140,000 patients in our registry.

The records of patients who have been seen at the institution within the year are updated by computer matches with information from appointment data, resulting in an updated "alive" status. In 2011, the last contact date was updated with the appointment date for more than 85,000 patients. Passive follow-up includes matching patients with a malignant diagnosis and a "vital" status of not known dead with death certificate tapes from the Bureaus of Vital Statistics (BVS) in Texas, New Mexico, and Oklahoma. Monthly death information from the BVS is compared with data for MD Anderson patients with cancer who are not known to be dead. Typically, data for more than 200,000 MD Anderson patients are compared with data for more than 15,000 new BVS-recorded deaths each month.

Active follow-up involves directly contacting the patient. The active follow-up process is separated into follow-up cycles during the given year to break the workload into manageable groups of patients. The active follow-up process includes selecting patients to be monitored in the cycle, creating computer-generated letters to be sent to patients, and making telephone calls to patients who do not reply to letters.

In the past year, more than 70,000 computer-generated letters were sent to more than 40,000 patients. A second letter is sent only if there is no response to the first letter, and a third letter is sent if neither of the first two letters is responded to. A maximum of three letters is sent, and the text of each of the three letters varies from that of the other letters. These letters have a response rate of 70–75%. Of the letter responses, 4 of 10 include a positive comment such as "thanks for your concern," "we appreciate your interest," or "thank you for caring." Patients who do not reply to the correspondence are contacted by telephone. This information is updated into the patient database, and the returned bar-coded letter is now scanned into the patient's chart.

A patient is eligible for a follow-up letter if the following criteria are met:

- Registered on or after January 1, 1962
- Not known to be dead
- Diagnosed with cancer (excluding non-melanotic skin malignancy)

From the above, the following patients are removed:

- Patients contacted within the past 12 months
- Patients with an appointment scheduled within the next 6 months

- Patients registered when younger than 18 years who are currently younger than age 18
- Patients with stop contact flags
- Patients in the Suspected Dead File (Hold File)

The follow-up letters are sent directly to the patient, not to a physician.

Death Processing

The three major sources of death information are (1) the Bureau of Vital Statistics of Texas, (2) follow-up letters and phone calls, and (3) communication from MD Anderson employees. The follow-up staff verify death information of more than 10,000 patients annually. A verified death list, averaging 900 patients, is distributed monthly to more than 40 MD Anderson departments.

Suspected Death File (Hold File)

The Follow-up Section maintains the Suspected Death File, also known as the Hold File. The Hold File is a database that lists all patients about whom death information has been received but not yet coded. The purpose of the Hold File is to avoid contacting patients who are suspected dead and to start the process of verifying their deaths. After the patient death has been verified, it can be coded and updated to the registry.

ACoS Follow-Up Results

In April 2010, the ACoS conducted an accreditation site visit at MD Anderson. The Tumor Registry's annual follow-up rates were calculated for the site visit based on the following ACoS criteria for identifying patients who are eligible for follow-up: (1) the patient has been registered since our reference date of January 1962; (2) the patient has a malignant diagnosis (not including carcinoma in situ of the cervix or basal or squamous cell skin cancer); (3) the patient is a U.S. resident; and (4) the patient is an "analytic" case (i.e., the first course of treatment was received at MD Anderson). Of the patients registered at MD Anderson between January 1962 and August 2009, a total of 148,942 analytic cases were, by ACoS definition, eligible for follow-up. The follow-up rates for this population were 92% of all patients and 97% for patients who were registered within the past 5 years.

Data Utilization Activities

The Tumor Registry database is designed to be used for clinical and epidemiologic research. The database contains demographic information about the patients and a

set of variables that are applicable to all cancers. The data allow a researcher to identify a population meeting specific criteria from which the researcher can focus on a specific topic. Because of the large volume of patients accessible from the database, researchers are able to have ample patients for retrospective case control studies, comparative studies within the institution's patient population, and survival studies comparing subsets of study populations.

The data are also used in combination with other data sets here at the institution, particularly data contained in the institution's data warehouse. The Tumor Registry data have been used to enhance financial data and operational data from our patient population that can then be used to analyze operations and projections for decisions on the institution's future operations, create financial models, carry out strategic planning, and determine market shares.

In addition to in-house use, Tumor Registry data are submitted to the Texas Cancer Registry and to the American College of Surgeons' National Cancer Database to fulfill the institution's compliance requirements.

Summary

In many ways, the functionality of the department has not changed much in the past 60-plus years. The mission of the Tumor Registry Department continues to be to collect, analyze, and disseminate high-quality data on each patient registered at MD Anderson. The abstractors continue to collect a well-defined and consistent set of data on each patient who registers at the institution. The follow-up staff continue to update the vital status of our patients. The epidemiologists continue to provide information to our researchers. In other ways, things have changed dramatically. Collection of data has moved from index cards to paper code sheets to electronic entry. Where once paper medical records, some weighing up to 20 pounds, were the only source for patient data, clinical information is now available virtually entirely in electronic form. Furthermore, the ability to link to other data sets within the institution has added tremendously to the value of the registry data.

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Chapter 3
Statistical Methods

Geoffrey G. Giacco, Sarah H. Taylor, and Kenneth R. Hess

Introduction

Long-term progress in cancer treatment can be assessed meaningfully with high-quality data from a cancer registry. This monograph examines changes in cancer survival by decade over a 60-year period at a single institution. However, these statistical assessments are subject to several difficulties in interpretation. These potential biases notwithstanding, measurements based on high-quality data that are collected in a standard way over a long period can add to our compendium of knowledge.

Patient Selection Criteria

The patient data used in this monograph came from The University of Texas MD Anderson Cancer Center Tumor Registry. To be included in the analyses, patients had to have registered and presented at MD Anderson between March 1944 and December 2004. Patients were included if they had received definitive treatment at MD Anderson but were excluded if they had received any cancer treatment before coming to this institution. Patients were also excluded if they had had primary tumors at more than one site, except for superficial skin cancers. If a patient had

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more than one primary cancer of the same site, the patient was included in these analyses only if the first of those cancers had been treated at MD Anderson.

Observed survival was calculated from the date of initial presentation to MD Anderson until the date of last contact or death. Ten-year survival analyses were performed for patients who initially presented between 1944 and 2004. This time span was selected because it would result in at least 10 years of follow-up for patients initially presenting between 1944 and 1999 and allow adequate follow-up for patients presenting between 2000 and 2004.

Time periods were defined in 10-year increments, except for the first period, which covered March 1944 to December 1954. The 10-year increments display changes in survival over the operating span of the institution. Although the break-points may not coincide with dates of changes in treatments that affected survival for specific sites, the narrative within the chapters will address those changes as appropriate.

Extent of Disease and Summary Stage

For all cancer patients registered since 1 March 1944, the MD Anderson Cancer Center Tumor Registry has captured the Surveillance Epidemiology, and End Results (SEER) stage of cancer at the time the patient first presents to MD Anderson. The SEER staging system is consistent across all cancer sites and therefore accommodates epidemiologic activities and comparisons.

The chapters in this monograph for solid tumors refer to localized, regional, and distant stages, which were based on the SEER stages [1]. Patients with *in situ* and unknown stages were included in the overall survival curves but were excluded from the stage-specific curves. In this monograph, only overall survival curves are presented for patients with lymphoma, leukemia, and myeloma.

The SEER program uses a basic staging system with five levels: *in situ* tumors are those that have not yet broken through the adjacent basement membrane. The term *localized* describes tumors, regardless of size, that are confined to the organ of origin. *Regional* tumors are those that have metastasized to the regional lymph nodes or have extended directly from the organ of origin. *Distant* describes a tumor whose metastases have traveled to other parts of the body or extended to a distant site (leukemia and myeloma are considered distant at diagnosis). When information is not sufficient to assign a stage, a cancer is said to be *unstaged* or *unknown* [2].

Follow-Up

The follow-up section of the MD Anderson Cancer Center Tumor Registry has maintained a 92–95% follow-up rate (based on American College of Surgeon Standards) for vital status in analytical patients over the past two decades. Patients who presented in December 2004 have potentially 55 months of follow-up at the time of analysis in August 2009. Most of the analyses were conducted in August 2009.

For further description of the follow-up procedures, see the "History of MD Anderson's Tumor Registry" chapter.

Analyses

Data were analyzed with use of PASW Statistics (formerly SPSS statistics) 17.0 (Chicago, IL). Survival-time distributions were estimated by using the Kaplan–Meier product-limit method [3]. This approach provides valid estimates of survival probabilities, even when patients are lost to follow-up or are still alive at the time of data collection. We used the trend-version of the log-rank test [4] to assess the differences in survival time distributions between groups. This test is sensitive to survival differences that are ordered with respect to the year of initial presentation at MD Anderson.

Potential Biases

Early Detection and Screening

The introduction of successful screening programs typically leads to earlier detection of lower-stage tumors and thus to improved overall survival rates (since patients with lower-stage tumors tend to live longer than those with higher-stage tumors). Therefore, observed improvements in overall survival rates may be the result of successfully implemented screening rather than the result of improvements in treatment.

In rare cases, a new screening program may result in the detection of cancer in the preinvasive phase and subsequent decrease in survival of invasive cancers (since such screening is more likely to detect lower-stage slow-growing tumors, but not the higher-stage faster-growing tumors, resulting in lower survival).

Although early detection due to screening may lead to changes in the overall survival curves, it does not affect the stage-specific survival curves. Thus, it is important to consider stage-specific survival in addition to overall survival when assessing changes in survival over long periods of time.

Changes in Diagnostic Criteria and Procedures

The introduction of new criteria and/or procedures for diagnosing cancer can lead to a phenomenon known as *stage migration*, which occurs because the new approach is more sensitive and leads to some patients being diagnosed at more advanced stages. In particular, as technology has improved, metastatic tumors have become

easier to diagnose; thus, in some cases, previously diagnosed local/regional-stage disease is now being diagnosed as distant-stage disease. As a result of this phenomenon, patients with the worst prognoses (i.e., those with occult metastatic disease) have been moved from the local/regional-stage designation to the distant-stage designation. Since these patients tend to have a better prognosis than do patients with frank metastatic disease, this "migration" from the local/regional stage to the distant stage resulted in an apparent improvement in survival among patients with a distant-stage designation. Since patients with occult metastatic disease (previously in the local/regional stage) tend to have a worse prognosis than do those with true local/regional disease, their removal from the local/regional stage designation resulted in an apparent improvement in survival among patients with a local/regional-stage designation. Thus, this instance of stage migration seemed to improve the survival of both local/regional-stage and distant-stage patients.

Although stage migration does not change overall survival rates for a given cancer, it can change stage-specific survival rates. Thus, it is important to consider stage migration as a potential explanation for improvements seen in stage-specific survival over time. It is also important to consider changes in overall survival in addition to changes in stage-specific survival.

Improvements in Supportive Care

Improvements in supportive and palliative care over time can lead to improvements in survival over time, even in the absence of improvements in cancer-directed therapy. Supportive care consists of nursing, respiratory therapy, physical therapy, cognitive therapy, behavioral therapy, cardiotherapy, infection control, and pain management, among others. Some improvements might be institution-wide, whereas others might occur in specific cancer clinics. Such improvements can lead to both improvements in quality of life for patients and improvements in survival and should be considered when interpreting improving trends in survival over time.

Changes in Patients' Prognostic Profile

Because our comparisons span such a long period of time, it is possible that the prognostic mix of patients with a particular cancer has changed over that period. If increasingly lower-risk patients were seen over time, then the overall survival may appear to improve over time, even without any improvements in cancer therapy. Since survival analyses are not adjusted for these changes in prognostic risk, care must be taken when interpreting improvements in survival over time. Improvements in survival may be wholly due to improvements in cancer-directed therapy, or they may be in part due to improvements in patients' risk profile.

Conclusion

This monograph assesses changes in cancer survival over a 60-year period at MD Anderson Cancer Center. For most cancer sites, we provide overall survival curves and stage-specific survival curves. We computed 10-year survival curves grouped by decade. In this chapter, we have described the methods used for identifying the patients for analysis, for collecting follow-up data, and for estimating survival curves. We also pointed out some potential biases that complicate the interpretation of the reported survival curves.

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Chapter 4
Breast Cancer

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Introduction

The treatment of breast cancer has evolved over the past 60 years. Earlier efforts, focused on achieving optimal control of local disease, ranged from radical mastectomies to lesser surgeries combined with irradiation. Surgery has been and remains an integral part of the overall therapy for this disease. With developments in therapeutic radiation technology at MD Anderson Cancer Center, the concept of breast-preserving surgery combined with irradiation became a reality in selected patients. In patients with locally advanced breast cancer, before the availability of effective systemic therapies, preoperative irradiation followed by surgery was a standard approach at this institution, and in a number of patients treated with this approach, adequate local control and long-term benefits were achieved [1] (Figs. 4.1, 4.2, and 4.3).

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