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How Did We Get To This Point?

by April G. Fritz, A.R.T., C.T.R.

Meet Susan Smith. In 1973, when she was 57 years old, she found a 4-centimeter mass in the upper inner quadrant of her right breast. Because she worked for an employer who had commercial insurance, she went to see a surgeon. The surgeon sent her to Memorial General Hospital for a mammogram, which was positive. The surgeon admitted her to Memorial General Hospital for some diagnostic testing—a chest X-ray and some skeletal X-rays. After two days, she underwent an excisional biopsy. The frozen section was positive for cancer, and she underwent a radical mastectomy within the same anesthesia. All of her lymph nodes were negative. She was considered to have a localized tumor. She was discharged after 10 days in the hospital. No further treatment was recommended. She is 21 years post-treatment and has had no recurrence. Her bill for the hospitalization (her total treatment) was $2,600 (in 1973 dollars).

Meet Jane Smith Doe, the daughter of Susan Smith. She knew she had breast cancer risk factors: no children and a positive family history of breast cancer. In 1993, when she was 49 years old, she had a screening mammogram through her employer who participated in a preferred provider organization (PPO). The mammogram showed clustered calcifications in her upper right breast. She went to her PPO doctor who examined her and referred her to a surgeon. He also ordered a diagnostic mammogram, which was done at a local radiology clinic. Jane then went to a surgicenter for a biopsy of the area. The biopsy was evaluated by an independent pathology office. Jane went to the outpatient clinic across the street from Memorial General Hospital for a bone scan and an abdominal CT scan. Finally, she was admitted to Memorial General Hospital one morning; that afternoon she underwent a lumpectomy. The tumor itself was 2.5 centimeters in size and was invasive. Her lymph nodes were negative, and her case was staged as a T2 N0 M0 Stage IIA. A tissue sample was sent to a reference laboratory for ERA and PRA analysis as well as DNA analysis studies. She was discharged the next morning. Jane was referred to the Cancer Care Center for radiation therapy, which she received over a period of six weeks. Jane's ERA and PRA were high, but the S-Phase was also high and her tumor was aneuploid. As a result, when she finished her radiation therapy, she was referred to a medical oncologist who decided to treat her in his office with six months of cyclophosphamide, methotrexate, and 5-FU. Jane's total medical bill for her first year of treatment was more than $28,000 (in 1993 dollars).

Susan Smith had one medical record in one doctor's office and one record in one hospital. Seventeen years later, Jane Smith Doe has parts of her cancer record in four physicians' offices, three radiology facilities, an independent laboratory, a reference laboratory, a surgicenter, a hospital outpatient clinic record, and an inpatient medical record. Jane's medical bill was more than 10 times what her mother's was.

How did American health care get to this point?

The short answer is that in response to the growing cost of medical care, the U.S. federal government, which has paid for the greatest share of cancer costs since the 1960s, has taken several actions in the past 30 years that have altered the way medical care was delivered.

What caused health care costs to rise in the first place?

Here the answer isn't so short. Health care costs in the past 30 years have been affected by several factors, including advances in technology, the aging of the population in general, and changes in federal reimbursement strategies, as well as overall inflation. Each of these is the sum of other factors, and each merits individual discussion.

TECHNOLOGICAL ADVANCES ADD TO HEALTH CARE COSTS

These mother and daughter vignettes show just how much American health care has changed in only two decades. Jane's treatment—even for a smaller tumor—was more comprehensive because her doctors learned more about her tumor from a battery of supplemental tests that did not exist in the 1970s.

The significant technological advances in the past 20 years just in treating breast cancer include:

- development and widespread

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implementation of low-dose mammography for screening and diagnosis
- reduced morbidity surgical treatment, first modified radical mastectomy and later lumpectomy and radiation therapy, both of which equalled or improved the survival rate of the disfiguring radical mastectomy
- the development of estrogen receptor assays and other tumor markers to aid in treatment decision making and provide better prognostic information
- recognition of the value of adjuvant chemotherapy for both node positive and node negative breast cancers
- the development of the anti-estrogen tamoxifen for long-term hormonal suppression and lower recurrence rates
- the identification of a breast cancer antigen, which may lead to a vaccine against breast cancer
- high-dose chemotherapy and bone marrow transplantation
- the use of cytokines (growth factors) that improve the recovery rate and reduce the toxicity of myelosuppressive treatment
- the beginnings of genetic engineering of the cancer cell, which can interfere with or reverse the neoplastic process and potentially cure the patient without surgery, radiation, or systemic therapy.

With the possible exception of the shift from radical to modified radical mastectomy, each of these technological advances has increased the cost of cancer treatment, primarily because these advances are supplements to treatment that provide additional prognostic information or improve quality of life or overall survival. The costs of these advances are notable, but they are compounded by additional factors: an increasingly aging population and an increasing incidence of and mortality from cancer in that aging population.

AN INCREASING CANCER-PRONE POPULATION

The growth in the cancer-prone population is the result of two factors: a baby boom generation that is advancing into its senior years and an increasing survival rate among people who have had other diseases—particularly heart disease and strokes. People are living to ages where cancer is increasingly common. The median age for all patients who develop cancer is 67 years; the oldest of the baby boom generation will be 50 years old in 1996. By the year 2011, the first of the baby boomers will be eligible for Medicare. In 50 years, more than 20 percent of the U.S. population will be age 65 and older. This profound demographic shift will have a massive economic impact.

In addition, for reasons as yet unexplained, the incidence rate for cancer among those 65 and older is increasing, as is the mortality rate from cancer. Between 1973, the first year SEER data were available, and 1990, the most recent year for which SEER data are available, the age-adjusted cancer incidence rate in the United States rose from 319 per 100,000 to 389 per 100,000, an increase of 22 percent. Over the same period, the mortality rate in the 65-and-older population from heart disease dropped from 45 percent of all deaths in 1973 to 39 percent of deaths in 1990, while the mortality rate from malignancies rose from 16 percent of all deaths in 1973 to 22 percent of deaths in 1990.

In short, more people are living long enough to develop cancer, more people are developing cancer, and more are dying from cancer despite advances in treatment. The number of new cancer patients diagnosed is expected to double by the year 2000.

As these factors continue to merge and build upon each other, the American Hospital Association estimates that cancer services will become one of the largest—if not the largest—revenue and cost centers (product lines) in hospitals by the end of the decade.

THE 1970s: REGULATION AND SPIRALING COSTS

Beginning in the early 1970s, the federal government sought to limit the cost of medical care by regulating the health care industry, including requiring hospitals to file certificates of need (CON) for new construction, expansion, or the purchase of expensive new technology such as computerized tomographic scanning (CT) or magnetic resonance imaging (MRI). Certificates of need were overseen by professional standards review organizations (PSROs). The federal government established PSROs in the community, and decisions could be appealed to state-level review organizations if the applicants were not satisfied with the local decision.

There were two major effects of the CON process. First, health care groups that desired new technology attempted to circumvent certificates of need by installing the new equipment in facilities owned not by the (regulated) hospital, but by groups of physicians or other investors. This was the first attempt to outsource services from the hospital, and the beginning of the disintegration of the unified cancer record.

Second, hospitals incurred substantial costs when preparing the CON documentation and dealing with the politics of obtaining approval, not to mention any lengthy appeals process that became necessary. These costs were passed along to the patient. Ultimately, more than 90 percent of CONs were approved, but the process had the opposite of its intended effect, and costs continued to rise.

The spiraling cost of health care was not totally the result of a failed attempt at federal regulation. As already noted, the 1970s and early 1980s saw quantum leaps in diagnostic and treatment technology, and each advance was more expensive for the patient. As an example, prior to the development of CT scanning, a metastatic skeletal survey (radiology) was the only means available to look for bone metastases. A cervical spinal X-ray costs in the range of $200-250 at 1994 rates. A computerized tomographic bone scan can find metastases that are not visible on the bone X-rays, but a cervical CT scan (with and without contrast) costs $1,000-1,300. The next technological advance for certain indications, magnetic resonance imaging, costs around $2,300 for cervical spine imaging with and without contrast, roughly 10 times the cost of a plain X-ray of the same area. However, when the diagnostic window moves from centimeters to millimeters, from Stage II to Stage I or Stage 0, new technology is quickly embraced by the patient and the physician despite the increased cost.

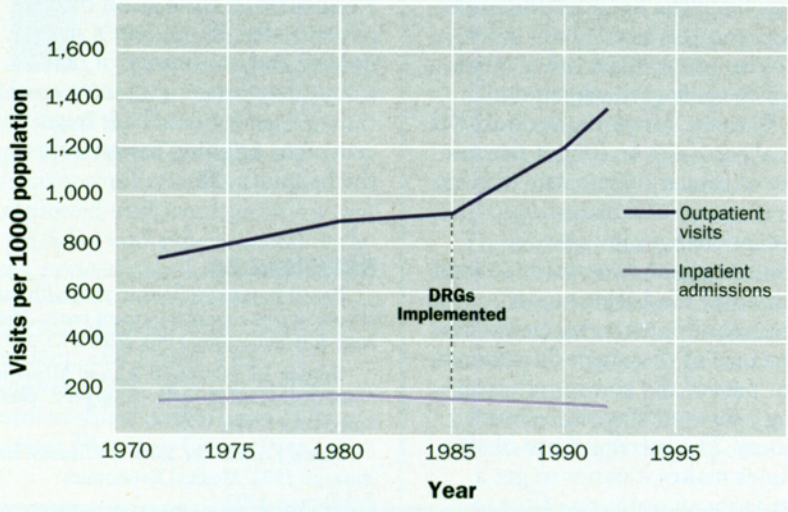
The demand for new services and hospital beds peaked at the beginning of the 1980s and actually began to decline. All the while, headlines screamed that Medicare was going to run out of money, and by the

time they reached age 65 there would be nothing for working-age Americans who were paying into the fund.

About this time, medical schools were graduating more physicians than the hospital health care market could assimilate. The number of specialty physicians grew as well. Prior to 1970 about half of physicians were specialists, and from the 1980s into the 1990s that proportion grew to two-thirds. Facing such competition, these young new physicians were willing to accept reduced charges to patients and, in many instances, longer hours of work in return for a guaranteed income. Thus, many physicians chose to become the employees of a hospital or managed care plan.

Responding to the increased competition, physicians opened independent clinics, urgent care centers, outpatient surgical centers, community radiology centers and laboratories, all of which maintained their own patient records.

Figure 1. Community Hospital Inpatient and Outpatient Visits 1972–1992



Source: U.S. Department of Commerce

THE 1980s: COMPETITION

Beginning in the early 1980s, the federal government decided to try competition rather than regulation as a method to control costs. In an effort to reward hospital efficiency, the federal government implemented the prospective payment system (PPS) in 1985. Prospective payment was a complete about-face from the previous reimbursement process, because instead of rewarding more charges with more reimbursement, the government proposed a flat fee based on the patient's diagnosis. After extensive investigation and evaluation, specific diagnoses that had similar costs were gathered into categories. Since 1985, these diagnosis-related groupings (DRGs) have been the mainstay of federal reimbursement and have been adopted by many commercial insurance carriers as well. With DRGs, if a patient had a diagnosis of surgically treatable lung cancer, the hospital knew in advance how much it would receive in reimbursement whether the patient stayed in the hospital three days or ten days. Thus, from the hospital administrator's point of view, it was to the hospital's financial advantage to make the patient's hospital stay as short as possible.

Hospital reimbursement is handled by Medicare Part A, which pays for inpatient treatment. With the advent of DRGs, hospitals began to shift various types of diagnostic and treatment procedures to ambulatory settings (hospital outpatient departments, freestanding clinics, and physician offices), where the procedure would be paid for under Medicare Part B, outpatient physician's fees, which have no DRG limitations.

As a result, more and more of the patient's diagnostic workup occurred before admission for surgery. And since there was little "brand loyalty" to the hospital, the patient most commonly chose to have tests close to home. This contributed further to the fragmented cancer patient record. Furthermore, after inpatient treatment, the patient perceived he was being rushed out of the hospital to recuperate at home, further reducing the hospital's costs to treat the patient. After all, a shorter than average length of stay meant an improved margin to the hospital. Between 1970 and 1994, the average length of stay for all diagnoses dropped from 8.1 days to 6.2 days. The number of hospital outpatient visits grew from 4.8 million in 1983 to 98 million in 1994. Overall, the number of inpatient admissions decreased slightly, while the number of outpatient visits skyrocketed (Figure 1).

As part of the shift from fee-for-service to prospective payment, managed care organizations expanded. At first heavily regulated in the 1970s, restrictions were lifted in the 1980s. Managed care organizations, including health maintenance organizations (HMOs) and preferred provider organizations (PPOs) added an additional twist to prospective payment by charging a fixed cost per month per person in the plan, thereby spreading the cost of treatment over healthy people as well as sick ones. The downside of this concept was that in order to reduce expenses, managed care organizations would limit physician and hospital choice, diagnostic testing (attempting to strike a balance between low cost and high yield of information), and even methods of treatment. Further restraints on patient care came in the form of utilization review (of resource consumption), second opinions regarding treatment, and preadmission certification (permission from the managed care organization for a patient to be admitted to the hospital for a nonurgent procedure). The decline in demand for beds and new services began to accelerate at this point.

By the end of the 1980s, prospective payment and managed care accounted for about 70 percent of a hospital's revenues, and 30 percent came from traditional retrospective, fee-for-service reimbursement. However, as federal and managed care payment guidelines paid for less and less, hospitals increased their charges to other payers to subsidize their costs of doing business. This cost shifting drove up the price of

commercial health insurance to employers.

MANAGED CARE: A NEW APPROACH FOR THE 1990s AND BEYOND

Employers turned more and more to managed care as a way of controlling costs, and by the mid-1990s, more than 17 percent of Americans were enrolled in some sort of managed care plan, up from 13.4 percent in 1990. In 1986, about 48 percent of U.S. hospitals participated in HMOs. That figure is predicted to reach 98 percent by 1996.

As cost-containment efforts by hospitals forced more and more services to outpatient settings or physician offices, physician charges soared. Recognizing this, the federal government changed physician reimbursement from fee-for-service to scheduled fees based on the Resource Based Relative Value Scale (RBRVS), a method akin to hospital DRGs. The RBRVS fee schedule, which began in 1991 and will be fully implemented in 1996, is based on the skill level required and the time involved (in other words, physician resources) to perform a patient service relative to other services provided by the physician. It is estimated that payments to general practitioners will increase 15 percent as they become the "gatekeepers" or managers of patient care, and that specialists will see a 5 to 25 percent drop in income.

All this competition had a remarkable effect on health care costs: the rate of increase actually slowed somewhat. Competition, combined with the threat of federally mandated health care reform, has turned the corner on spiraling costs, but they are not yet under control.

THE FUTURE OF THE CANCER PATIENT RECORD

The cancer patient record may have disintegrated as far as it will. Even at its present stage, however, a fragmented patient record remains a problem for members of the cancer management team—consultants, nurse specialists, support staff, cancer registrars, and others, including cancer program administrators. Many times the managing physician carries in his or her head information—such as the details on which staging (and therefore treatment) is based—needed by others on the patient care team. Such details should be dictated into the hospital record so that everyone will have access to them.

For all members of the cancer team to complete their jobs, they must be able to find answers to questions about extent of disease and multidisciplinary therapy in the medical record. Unless the managing physician makes an effort to incorporate these scattered reports into the hospital record, that legal document is incomplete.

It may be that the most complete cancer patient record develops in the managed care organization's office, where copies of reports sent to the primary care physician would be delivered. Unfortunately, this office is away from the hospital where the patient record is needed as a reference by specialists and other members of the cancer management team. Clearly, however, the hospital medical record is no longer the sole source of cancer diagnostic, staging, and treatment information.

Recent changes in Joint Commission and American College of Surgeons' Commission on Cancer requirements emphasize the importance of thorough documentation as part of the communication among cancer management team members. The increased use of fax machines makes it easier to get a report from an outlying office to the hospital.

The computerized patient record (CPR) may solve the problem of handling reports from scattered sources. However, a report generated outside the facility must still make its way into the facility to a location where it can be scanned into the CPR, which takes human intervention and effort.

The quality and completeness of the cancer patient record will become crucial in a time when the patient's extent of disease and course(s) of therapy must be communicated to a growing list of health care providers. In addition to nurses and physician assistants, who will assume more and more hands-on patient care, the cancer patient's story will be reviewed by utilization managers and outcomes measurement analysts, just to name two groups on the outskirts of direct patient care.

Even the cancer program administrator faces the challenge of a fragmented cancer record. Now that capitation and carve-outs are factors in bidding managed care contracts, the hospital must be aware of the complete cost of diagnosing, staging, and treating the patient, including all those tests and procedures performed outside the hospital. Without a concerted effort by all members of the cancer team to incorporate their findings into the hospital cancer patient record, communication will be hampered, and patient care decisions may be based on incomplete information.

Whose responsibility should it be to ensure complete documentation of the patient's cancer? The answer will depend on the hospital's relationships with the cancer care team and the outlying reporting sources. Regardless, for the good of the patient—for the patient's service quality and continuity of care—a complete cancer patient record and cancer registry data base must be central to ongoing cancer care in the hospital.

REFERENCES

Bazell R. Growth industry: Health care reform versus cancer treatment costs. *The New Republic,* 208(11):13, March 15, 1993.

Bunker J.P., Barnes B.A., and Mosteller F. *Costs, Risks and Benefits of Surgery.* Oxford University Press, 1977.

Burns J. et al. *The State of Health Care in America 1993.* Medical Economics Publishing, 1993.

Einstein A.B. The challenge of change. *Oncology Issues,* 8(2):5, Spring 1993.

Everson L.K. Cancer program development in the 1990s. *Oncology Issues,* 8(2):8-10, Spring 1993.

Everson L.K. and Vandergrift T. Cancer program development in the 1990s: Survival in a managed care environment. *Oncology Issues,* 8(4):14-16, Fall 1993.

Health News Daily, July 26, 1994.

Lerner M. Access to the American health care system: Consequences for cancer control. *CA, A Cancer Journal for Clinicians,* 39(5):289, September-October 1989.

Miller B.A., Ries L.A.G., Hankey B.F., Kosary C.L., Harras A., Devesa S.S., and Edwards B.K. (eds). *Cancer Statistics Review, 1973-1990,* SEER Program, National Cancer Institute. NIH Pub No. 93-2789, 1993.

Mortenson L.E. Understanding cancer reimbursement. Chapter 79 in *Cancer Nursing* (at press).

American Hospital Association. National Hospital Panel Survey of Economic Trends, excerpted in *AHA News,* page 4, September 12, 1994.

Personal communications with staff at Dianon Systems, Nicholls Institute, various radiology centers.

U.S. Department of Commerce Bureau of the Census. *Statistical Abstract of the United States 1994.*