The Cancer Patient

Social and Medical Aspects of Care

Barrie R. Cassileth

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Edited by

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Preface

Cancer, both the word and the disease, has profound impact upon our sensibilities, our responses as a society, and our medical activities. From the time of the hieroglyphic injunction about certain tumors, "Do thou nothing there against!" to the more recent declaration of war against the disease, cancer has evoked powerful emotional reactions that contribute importantly to the meaning of cancer patienthood and to the management and care of patients with malignant disorders.

The chapters in this book collectively represent an attempt to explore the multifaceted significance and problems of this disease. Cancer is much more than cellular dysfunction. It is an historic event; a conceptual bias; a social, economic, and ethical dilemma. It touches patients, families, and care-givers in subtle ways of which most remain unaware, knowing only the unease, the sense of fear and wrong. It raises special issues in clinical management, such as refractory pain, severe malnutrition, and rehabilitation challenges. Texts on oncologic

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Part I

Social and Cultural Dimensions

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The Evolution of Oncology as a Sociomedical Phenomenon

Barrie R. Cassileth

CANCER is a long-recognized disease, but oncology is among the most recent of medical specialties. Throughout the 4,500 years between the earliest known reference to cancer and its treatment (Edwin Smith papyrus)[1] and the 1978 appropriation of approximately $1 billion to the National Cancer Institute, the symbolic power of this disease has helped define and organize attempts to combat it. The development of oncology as a medical specialty reflects the ebb and flow not only of technical advance and scientific ideas, but also and equally of cultural values and beliefs. The quantity and thrust of federal appropriations for cancer-related work are illustrative. These appropriations are less indicative of the rational and relative "need" for such funds than of the symbolic meaning of the disease itself. Disorders of the circulatory system kill more people, eight other illnesses impose greater limitations on

activity, and cancer ranks only sixth among reasons for hospitalization.[2] But federal legislators appropriate more than twice as much money to cancer than to any other illness.[3] Cancer is imbued with special meaning and it evokes a unique dread. It represents, perhaps, the "wisdom of the body"[4] gone awry, and financial outlays to combat it symbolize our efforts to cope with the fear and inexplicability of an invisible and seemingly random process. Social conceptions and misconceptions about cancer have determined public support of activity related to this disease, played a role in the kinds of facilities erected to house the cancer patient, and helped guide the development of oncology as a specialty science. The history of the emergence of cancer medicine reflects the interdependent nature of scientific and popular ideas, therapeutic advance and research technology, and an enduring cultural framework of reaction to the homeostatic derangement which cancer seems to represent. The following review is an attempt to integrate the various symbolic, social, and scientific elements that in a mutually influencing fashion led gradually but only recently to formal recognition of the specialty of oncology, to development of the specialized cancer treatment setting, and to the reigning belief system that cancer should be attacked with research, with money, and with aggressive treatment.

Twenty-four centuries ago Hippocrates delineated many forms of cancer, named it *karkinos* (carcinoma) because the swollen veins sometimes associated with tumors suggested the claws of a crab, and identified the illness as natural rather than magical or divine in origin.[5] Treatment of the disease is also ancient. Arsenic pastes were applied to spreading growths 500 years B.C., and in Galen's time primitive local tumor surgery was performed. By the sixteenth century, cancer's metastatic potential had been recognized and benign and malignant tumors differentiated. There was enough to say about the illness by 1721 for a surgical encyclopedia published that year to devote 210 pages to "cancer" and "tumors."[6] The eighteenth century also saw the foundation of the first cancer hospital, created by Canon Godinot in 1740 in Reims, France,[7] and development of the first cancer service in a general hospital, Middlesex in London.[8] In what was the earliest recognition of an occupational or environmen-

tally induced carcinoma, scrotal cancer of chimney sweeps was described in 1775 by Percivall Pott, who developed a surgical cure and propounded social legislation which eliminated the disease within two generations.

A landmark in the social history of cancer occurred with two important changes during the seventeenth and eighteenth centuries. Each of these shifts in perspective had important social and scientific impact, the ramifications of which are felt even today. First, the conclusion of Zacutus Lusitanus (1575–1642) and Daniel Sennert (1572–1637), two highly influential clinicians, that cancer was contagious led to construction of isolation facilities for cancer patients.[9] Their views, along with remnants of the Middle Ages belief in cancer's incurability, created a leprosy-like aura for cancer in the public mind and initiated the sense of shame, horror, and stigma with which cancer became invested. The stigma thus associated with the disease played a major role in shaping attitudes and retarding the eventual development of cancer as a medical specialty. People first had to accept cancer patient status, and they had to believe that medical care could help them, before cancer medicine could become a reality.

Second, and apart from this public perspective, a shift occurred in scientific understanding of the disease. During the eighteenth century the humoral, total-body-invasion view of cancer, which had dominated professional conceptions since antiquity, gave way to precursors of modern, localistic understanding of the disease. LeDran, for example, emphasized the local origin of cancer and its dissemination through the lymphatic system.[6,9] This perspective facilitated the many ensuing distinctions between cancerous and noncancerous manifestations of the disease and fathered contemporary understanding of cellular pathology. Most important, this new perspective permitted the assumption that cancer starts as a local disease which can be cured if found early enough.

By the end of the nineteenth century a complex disease with numerous manifestations had been recognized. It could be diagnosed, treated, sometimes cured, and studied. A patient population was identifiable from both the physician's and the patient's points of view. Special hospital facilities, such as that built in 1889 in New York, had been established exclusively for its treatment. But critical cultural and organizational

prerequisites were still lacking, and cancer did not emerge as a medical or surgical specialty at this time. There were, however, precedents extant for specialized activity.

Although most mid-nineteenth century physicians practiced in rural areas as surgeon-physician-midwife generalists, some hospitals and doctors in major cities had begun to focus on specific diseases and anatomic sites, marking the beginning of a trend to specialization in the delivery of medical care. At mid century, for example, the city of Philadelphia alone had maternity, children's, mental, and orthopedic hospitals, as well as dispensaries for eye and ear, chest, gynecologic, and dermatologic care. Similar specialty hospitals were located in other major cities.[10] Early specialization in clinical areas such as pediatrics, internal medicine, and general surgery suggests that specialty practice did not evolve along organ systems alone. It should be noted that emerging medical specialization in the nineteenth century hardly was innovative. In the fourth century B.C., Herodotus wrote:

> The art of medicine in Egypt is thus exercised: one physician is confined to the study and management of one disease . . . some attend to the disorders of the eyes, others to those of the head, some take care of the teeth, others are conversant with all diseases of the bowels; whilst many attend to the cure of maladies which are less conspicuous.
>
> (Histories, II.84)

Also marking the trend to medical specialization during the nineteenth century were new developments in the social organization of health care professionals. Several American societies—otologic, ophthalmologic, neurologic, gynecologic, dermatologic, laryngologic, surgical, climatologic, pediatric, and other specialist associations were founded before the end of the century. Specialist chairs began to appear in hospitals, and many urban physicians practiced in specific clinical areas. Long legitimated by professional and social activity, specialty practice began to receive formal sanction in the early twentieth century. In 1916, ophthalmology became the first recognized medical specialty. Six years later, 11% of all practicing physicians specialized in specific illnesses, age groups, body organs, or techniques. By 1957, 41% were

specialists, and by 1967 specialists comprised 71% of all practicing physicians.[11] By that date, there were 22 separate specialties and subspecialties, each with its own residency requirements and certification examinations.[12] Oncology was not among them.

Although not formally recognized as such, oncology had long since attained specialty status in practice. The term medical specialization is used frequently to denote areas of medical practice, such as ophthalmology, which have been legitimated by virtue of approved training programs, licensing requirements, and examination certificates. Official recognition of the very existence of such specialty areas, as well as entry to them, is controlled by 22 boards as of 1976, such as the American Board of Ophthalmology, the American Board of Surgery, and the American Board of Internal Medicine. Many boards certify in subspecialty areas as well. Thus a physician specialist may be so defined according to organized professional standards and requirements. Specialization, however, also denotes a kind of professional activity in which physicians engage, even in the absence of official sanction or certification. Physicians often specialize in areas which have been board licensed, even though they themselves may lack a certificate. Approximately 60% of all physicians in specialty practice are board certified.[13] Thus, substantial numbers of specialists have not sought or been awarded diplomas from the various specialty boards in existence today.

Unlicensed de facto specialization in cancer medicine occurred well before its official recognition. With that recognition came a new name. Medical oncology, a subspecialty of internal medicine devoted to the total care of the adult cancer patient, was officially legitimated by a three-step process. In February of 1971, the American Board of Internal Medicine decided to offer certification in this subspecialty area. Approval for establishment of the field was granted by the American Board of Medical Specialists one year later, and the first medical oncology certifying examination was administered in October, 1973.[14] That date marks official recognition of the specialty. De facto specialization, however, has no analogous definitive signs. Physician-authors often construe technologic developments as such signs, and suggest that medical specialization is fostered and evidenced by new

medical knowledge and technique. Sociologic explanation too sometimes reflects this position: "Specialization is an aspect of increasing knowledge and the resulting variety of skills in a profession. It follows modern science as shadow follows substance."[15] But increased knowledge and new skills do not necessarily culminate in the emergence of a new specialty area. Developments in technique and knowledge characterize each decade in the history of medicine. The scientific advance hypothesis fails to explain why one development rather than another gave rise to the new professional segment.* Further, the technical advance criterion permits selection of any important discovery, and citation of it as harbinger and proof of a new specialty's arrival. If technologic landmarks are insufficient criteria, one must look elsewhere to pinpoint the temporal emergence of the specialty of oncology and to uncover those elements that produced the professional oncologic community.

Several characteristics typify the growth of medical segments. These include claims to unique professional capabilities (a sense of mission); development of particular professional activities that define core tasks, techniques, and clients specific to that segment; and the establishment of colleague relationships and professional organizations.[16] Along with such professional activities and maneuvers toward segmentation, elements external to the profession are prerequisite. Broad cultural legitimation is required before a segment is recognized and can function as a full-fledged medical specialty. Evidence of public acceptance, as well as professional activities that characterize specialization, are explored in the following sections. Creation of unique roles, specialty associations, publications, techniques, and colleagueship patterns are signs of emerging specialty status, as are attempts to categorize and disseminate data.

During the nineteenth century, the confusing welter of growths, lumps, and masses which together had been called "tumors" or "cancers" were classified into malignant versus nonmalignant categories. Further categorization occurred

*This kind of explanation, however, may be appropriate with regard to emergence of basic science segments. Invention of the microscope, for example, was prerequisite to establishment of histology and bacteriology as research specialties.