

Physician's Guide to Cancer Care Complications

Prevention and
Management

edited by
John Laszlo

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JOHN LASZLO

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Preface

We try to teach young physicians that just because a patient has cancer we should not omit care that can extend or improve upon the quality of life; however, we must not automatically initiate "standard" and expensive treatments if these are meddlesome and likely to cause more harm than good. Nevertheless, errors of omission or commission are made easily even by experienced oncologists, and we try to learn from each patient and build a sound knowledge base over the course of a lifetime of practice and therapeutic trials. This book recognizes that we have some very potent therapeutic tools at our disposal, thanks to advances made in the last half-century in surgery, chemotherapy, and radiation therapy. Our purpose, however, is to identify the many potential hazards that go with usage of these therapies, some of which can be anticipated clearly and therefore eliminated, minimized, or otherwise prepared for in the context of an effective therapeutic alliance. We address the issues of identifying the unique needs of the patient and family, and suggest means with which to satisfy these needs in the hospital, clinic, and home.

The physician is required to orchestrate the care of the patient, but the implementation of total care is largely the function of a multidisciplinary group that often includes nurses, social workers, chaplains, recreation therapists, technicians, other health professionals, and volunteers. The contributions of our expert authors are partly technical and partly experiential. Although the technical fields are changing rapidly, we trust that the wisdom regarding how to approach such changes will endure and continue to serve us, as we serve our patients with compassion.

John Laszlo

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Introduction

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Contrary to some impressions which the public may have, the fields of medicine and medical research do not always progress in smooth and orderly steps. They are subject to the same sorts of chaotic events as are the thought processes of its practitioners, the unanticipated finding, or the application of a discovery from one scientific field to another. Furthermore, medicine has always been susceptible to fads regarding what is and what is not scientifically acceptable, and it is being influenced increasingly by what the public thinks it wants.

Evolution of the discipline of clinical oncology is an important example of these influences; venereal diseases would be another, more limited, case. So many centuries of benign neglect of the patient with advanced cancer were generally consistent with the stigma associated with this disease. Surgeons dominated the field of oncology because their methods were potentially curative for patients who had localized disease. When radiotherapists began to show that palliation was possible even for patients with advanced disease, they—together with other physicians interested in medical oncology—began to take an interest in patients with advanced cancer. The development of chemotherapy in the past quarter century has caused great optimism among the medical community that cancer may be curable if only the right drugs can be found for the common tumors. Indeed the field of medical oncology has grown so rapidly that there is considerable concern that we will soon have an excess of specialists. Surgical, medical, and radiation oncologists have all

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developed new approaches to diagnosis and to treatment which lead to greater curability in some types of cancer, and longer survival if not cure in still others; unfortunately there is too large a group of patients whose survival is not enhanced by our skills. The fields of oncology nursing, social work, and recreational therapy are fast becoming established at larger institutions as those voids in provision of care are being filled by those who have special training.

The public is far better informed (sometimes misinformed) about cancer and much more willing to question the doctor about treatment alternatives. They are concerned about the cost of being treated, and this includes the medical, social, and financial costs. With respect to finances, doctors are often unaware of the enormous economic burdens that we inflict with unnecessarily elaborate and even unproductive workups and therapy. Rehabilitation programs have been developed for the patient who has lost a body part, in response to the needs that these patients face. It is easy to recognize the concerns of an amputee who wants to return to a job; it is more difficult to understand the psychological disruption suffered by a patient who has undergone a mastectomy or faced the consequences of chemotherapy. The failure of our system of medical care (with exceptions, of course) to adequately provide for terminally ill patients—to palliate, to maintain the family structure, and not to deplete the last dollar in the process—has led to the dissemination of programs that provide hospice types of home care throughout the United States. The remarkable rapidity of public acceptance of this health concept may be unprecedented in this nation, and it should cause us to examine the limitations of some of our other cancer programs.

In evaluating the clinical programs of the Duke Comprehensive Cancer Center we have been struck repeatedly with the need to develop better means of responding to the diverse human concerns of patients; at the same time we strive to provide cures or significantly prolong their lives. The means of delivering first-rate supportive care for patients with chronic diseases such as cancer are still not well developed, as our daily experiences with patients reminds us. There has been sporadic, inspired, and major progress in use of blood products, diagnosis and treatment of infections, venous access, and antiemetics. Still, there has been little systematic research in supportive care, and the measurement tools available for assessing the needs and concerns of patients are often inadequate for the task.

Attention to the human needs of patients (i.e., pain control, nausea and vomiting, psychological problems) has taken on a relatively new and large part of the oncology literature. However, the subject of how to *anticipate* and *prevent* some of the complications of cancer and its potent treatments has not been systematically addressed. Although there clearly is an overlap with treatment of established complications or of conventional rehabilitation methods, the emphasis of this book differs in a significant fashion. Let us discuss openly that many of the things we do to treat patients have risks—some mild,

some life threatening, some rare or common. We contend that many of the complications of cancer and particularly of its treatments are predictable and often quite preventable. Indeed the standard of practice should dictate that all reasonable preventive steps are taken and also that the patient is advised when there is a significant risk that treatment will produce disability. To the extent that prevention is preferable to treatment or rehabilitation, then clearly our patients would be grateful for progress along these lines.

This is a time of great change in expectations: patients want to be permanently cured of cancer and they certainly expect to be kept free from suffering during treatment if cure is not possible. It was not long ago that doctors had no tools to do more than manage the simpler ills and for alleviating some of the pain and suffering, if not all of the anguish, of chronic illness. Though not wanting to return to those days, we should not now substitute more advanced technical skills at the expense of practicing those older arts of medicine, though there are admittedly powerful forces pushing young doctors in such directions. One semiderogatory term that one sometimes hears from patients is that their doctors are overly "aggressive." And yet there need not be a conflict between technology and wisdom if one is aggressive in evaluating the total situation and dealing not only with the possible, but also with the most desirable choices, as seen from the viewpoint of the patient. Since there are often numerous choices to be made, the issue of minimizing the harm would seem to be a natural part of the decision-making process. We hope that by informing the reader about the potential complications of the various treatment options (versus the admittedly grim natural history of the disease itself), many problems can be avoided and the entire process of setting goals will become transparent to all of the participants. The subject matter dealt with in this book is quite diverse, from the imparting of highly technical knowledge to sharing our thoughts on philosophy, care of the young or elderly, and economics. Indeed, we do not guarantee that we will always be consistent in approaching controversial topics from different points of view. Nonetheless, the unifying theme of the book is that a gentle and thoughtful approach, one capable of being modified in accordance with changing circumstances, is most compatible with the highest professional calling that we can offer to the people we serve.

Most of the contributors for this book are drawn from the members of the Duke Comprehensive Cancer Center. They were encouraged to develop a "state-of-the-art" representation on the subject of prevention of complications, not an encyclopedia of cancer treatment, nor a recital of what various specialists do. The challenge was to effectively integrate overlapping fields of endeavor and to refer to other sources of information when pertinent. We might begin that process by referring to a selection of recent books which can be used to supplement some sections of our book (Rosenbaum and

Rosenbaum, 1980; Zimmerman, 1981; Cassileth and Cassileth, 1982; DeVita, Hellman, and Rosenberg, 1982; Holland and Frei, 1982; Higby, 1983; Laszlo, 1983; Wiernik, 1983; Perry and Yarbrow, 1984).

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2

Goals of Patient Versus Goals of Physician

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I. INTRODUCTION

Fortunately, the practice of "protecting" patients from learning about their diagnosis of cancer is rapidly disappearing, at least in the United States. The advent of mandatory informed consents for protocol studies which are used in all oncology training programs, a well-informed lay public, and the popularity of being an assertive patient have all influenced the mores of the health professional. Indeed, the horrors of Solzhenitsyn's Cancer Ward where the patient describes himself as "a grain of sand" are hopefully relegated to the past. However, it is possible that the pendulum has swung too far in the other direction in the arena of "supportive care for cancer patients," which, while arguing for openness of communication, creates a demon that insists on deluging patients with facts about major complications that have only the slightest possibility of ever occurring in their specific case.

Emphasis is often placed on the physician to meet the objective of divulging a set body of information about the disease and treatment, rather than on a continuing interactive communication between patient and provider. The reader may recall classroom experiences where the teacher was frantically intent to cover certain information (teaching) and the students in turn were frantically taking notes but were totally confused. In that kind of setting the teachers were too busy "teaching" and not concerned with their primary purpose of assisting the students to learn.

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The purpose of this chapter is to present information about how a direct approach to the patients' concerns can successfully be achieved. Although such an approach may be time consuming initially, it is so simple and effective that it is a wonder more doctors have not mastered this communication skill. Indeed, the failure to communicate increases the likelihood of noncompliance with therapy, among other problems, which in turn evokes feelings that further erode the patient-provider relationship, and this has psychological, medical, and legal ramifications.

The chapter presents pragmatic approaches that can be used to ward off crisis points that cancer patients frequently face. Information is presented based on the continuum of disease progression leading from cure, control, or, unfortunately, death. Strategies are presented that when employed or suggested can have a high probability of avoiding or delaying complications. Special attention is given to increasing sensitivity regarding potential disparity between the goals of the patients and provider. It is hoped that the disparity once recognized can be avoided by development of a successful therapeutic alliance.

II. SENSITIVITY TO GOAL DISPARITY

At first even the well-adjusted patient may have a lingering doubt about the accuracy of diagnostic tests, namely, "is it really cancer?" If there is no reasonable doubt then we explain the facts and treatment options—including no specific treatment or the option of delaying treatment. Discussion of the pros and cons of each option must include the necessary factual exposition and time for questions, and all questions will not necessarily be voiced at this first meeting. We can anticipate spoken or unspoken questions about unconventional treatments, the possibility of cure, life expectancy, a second opinion, causes of the cancer and whether it is contagious. If other key individuals (spouse, offspring, parent) are included in the conferences, the perceptive physician can quickly grasp the family dynamics—strengths, weaknesses, and concerns—and tailor the presentation to cover all the essentials. It is impossible to anticipate every possible concern without a thorough discussion, and time will not generally permit a full discussion with a succession of concerned family members or friends. If drug program A is unlikely to cause alopecia, that may be particularly reassuring news to this patient: if alopecia is likely, then advanced warning and advice about short- and long-term solutions will undoubtedly be appreciated.

A major goal at this point is to provide as much information as the patient wishes to have. Sometimes patients make it clear they are not ready to deal with the issues, and yet from the very beginning a major goal is to encourage the patient to have input into treatment decisions. It is important that the patient will be interacting with a competent and caring team who will be there

to help. Specific instructions about whom to call with further questions (or in case of emergencies) will be quite reassuring, since afterwards there is bound to be concern that not all pertinent questions were properly anticipated or asked. In the long run it is more important for the patient to feel this kind of confidence than it is to cover every possible contingency in an overly encyclopedic presentation.

Often mere willingness to discuss the possibility that a recommended treatment might cause side effects instills confidence in the candor of the physician: it sets the stage for future honest communication, and facilitates acceptance of other complications, even those rarer ones that were perhaps not discussed. Indeed, in arguing for openness of communication we do not feel it is necessary to deluge each patient with every rare complication that might conceivably occur—the point can easily be made that beyond the more common complications there are others that are rare, unpredictable, and potentially very serious and even life threatening (so after all is the untreated disease). This type of climate creates a kind of trust that will go a long way towards defusing problems which are bound to arise at home between visits to the doctor. If there is reason to believe that key pieces of information will be needed by the patient or family at a later time, then the entire discussion can be recorded and given to the patient to keep. In the educational process it is useful to anticipate common concerns about pain or financial costs, and to reassure the patient that those problems will be addressed should they arise. These issues of communication with patients have been thoroughly discussed by Rosenbaum and Rosenbaum (1980).

Concerns and attendant behaviors associated with cancer can arbitrarily be divided into those which occur around the time of diagnosis, those which occur when there is evidence of tumor recurrence or progression, and those which occur during the terminal phase of illness. However, events preceding the time of diagnosis are also worthy of consideration: perhaps the patient had life experiences which caused awareness of the risk of cancer, such as high family incidence or carcinogen exposure, and chose some type of coping strategy from among a wide range of options; there may have been purposeful attempts at cancer detection, deliberate avoidance of known carcinogens, lack of interest, or denial. The past history can sometimes help to explain the surprise, guilt, anger, or denial which accompanies news that the diagnosis is cancer. Further, a person who has a long history of exposure to asbestos or cigarettes is conditioned to deal with lung cancer differently from someone who has not had that history, and if the spouse has been complaining for years about the exposure then the family dynamics could be adversely affected throughout the course of the illness.

When a diagnosis of cancer is first established, the options are finite, although still numerous. As the disease progresses and death becomes imminent

the available choices become further constricted. It is often at this point that patients are referred to large centers to be cared for by specialists. By then the limited available options make it progressively more difficult for individuals to exert control over circumstances which affect their lives and welfare. Thus, from a clinical vantage point it seems clear that for patients who are not cured, the disease moves through a continuum during which the options for both patient and care provider diminish. During the course of the illness the health team periodically redirects its goals: these are initially curative in intent and are later geared towards palliation; although they generally parallel those of the patient, the specific concerns of the two parties may at times be so different as to become conflicting.

In a study of 26 veterans with advanced cancer, considerable disparity existed between patient and staff (doctors and nurses) perceptions (Nehemkis, Gerber, and Charter, 1984). Interestingly, oncology specialists tended to overestimate the importance of pain to the patient and to underestimate the value of simple daily activities such as being able to perform household chores and the sense of loss from disruption of leisure activities. In a more circumscribed study of patients' and physicians' perceptions as related to the consent form for participation in an investigational protocol (Penman et al., 1984), marked differences did exist. For example, 91% of patients thought that their physician wanted them to accept, whereas physicians thought that most of their patients were truly expressing their own preferences and only one-third were passive in their acceptance.

The disparity between the goals of the patient and provider may be in part related to a frequent clinical observation that with progressive illness the patient develops a shorter time frame for his/her concerns: this contrasts with the patient who is less ill (or the normal mature individual or health professional) and has a long-range perspective. A short-term outlook is not unique to terminally ill cancer patients, but occurs also in patients with other chronic illnesses who feel threatened or assaulted by dangerous or toxic procedures or by therapeutic interventions. We might say parenthetically that not much is known about the time frame changes that go on in family and "significant others." We have schematized our concept of these general issues and their effects on patient and staff in Table 1, without intending to specify the priority or to suggest that this is an exhaustive list of factors relevant to any given clinical situation.

Although other patients with advancing chronic illness experience a narrowing of options and time frame, cancer and cancer-related treatment seems to have an especially noticeable impact on patients and family. Unfortunately, all cancer treatments cause some degree of damage to the patient and they are often accompanied by physical and emotional discomfort. Some studies have compared the toxicity and psychological effects of treatments

Table 1 Issues Which Affect the Patient and Health Team at Various Times During the Illness

Diagnosis questions, concerns, and fears	Progression	Terminal
Patient		
Correct diagnosis?	Side effects of Rx	
Life expectancy?	Alternative therapy	
Best doctor and hospital?		Need for hospitalization vs. home care (Hospice)
Causes of this cancer?		
Contagious?		
Curable?		
Dying	Dying	Lack of communication
Family	Making family plans	Abandonment
Pain	Pain	Pain control
	Weight loss	Ambulation
Sexuality and body image	Nausea and vomiting	Bowel and bladder
Expenses	Venipunctures	Fear of unknown
Business	Expenses	
Activities of daily living		
Physicians and staff		
Accurate diagnosis	Family support	Emotional support to patient and family
Extent of disease	Home needs	
Co-morbid conditions	Planning salvage Rx	
Informing patient and family	Palliation of symptoms	Palliation
	Prevention and treat- ment of debility	
Developing therapeutic options	Vein infiltration	
Surgery	Malnutrition	
Radiation	Infection, bleeding, fractures	
Chemotherapy		
Immunotherapy		
Hormones		

Note: This is a partial and schematic simplification to illustrate differences in perspective. The dotted lines are intended to symbolize the progressive constriction of available options.