CARE OF THE TERMINALLY ILL CANCER PATIENT

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CARE OF THE TERMINALLY ILL CANCER PATIENT

A Handbook for the Medical Oncologist

By

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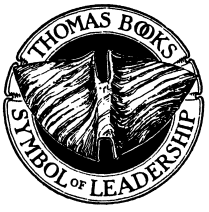

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PREFACE

Approximately 550,000 Americans will die of cancer this year. Most of those patients will be under the care of an oncologist. This places the oncologist and his or her team in a unique position to favorably influence end-of-life care for cancer patients. The SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment) studies published in 1995 indicate that there are significant deficiencies in the care of our dying patients. We need to become more effective in pain and symptom management as well to improve our communication skills. Moreover, we need to apply these skills much earlier in the clinical course. In most cases, we should be prepared to offer and deliver good palliative care from the time of diagnosis for our cancer patients. Most of the texts written on palliative care are done so from the generalist's perspective. Those of us who take care of cancer patients would probably agree that there is something very special about our patients. The problems and solutions in cancer care are not the same as those found in general medicine. It is the purpose of this book to provide a guide for development of skills to improve care of our dying cancer patients, and to urge application of those skills earlier in the course of cancer treatment.

M.R.O.

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Chapter 1

THE MEDICAL ONCOLOGIST AND THE CANCER CARE TEAM

Texts that focus on *end-of-life* care are not usually considered integral parts of the medical oncology curriculum. Indeed, coverage of end-of-life care issues is sparse among medical texts in general (Carron, Lynn, & Keaney, 1999). Attention to the special needs of dying patients and their families is a relatively recent emphasis in cancer care. Our efforts for our cancer patients are directed primarily at curative therapy, and this is as it should be. It is what our patients expect. Successful cancer treatments are big news. Much less attention is devoted to those situations in which treatment is unsuccessful. It is often difficult to acknowledge that so many of our cancer patients will succumb to the disease, even though we are faced with this reality on a daily basis. To direct time and resources to care at the end-of-life requires a major shift in focus, and this is often a very difficult transition for the medical oncologist and the cancer care team. "Where cure is the ultimate goal, death is the ultimate failure" (Fox, 1997). It is also one of the greatest opportunities that we have for having a positive impact on the quality of life of our patients.

There is something special about care of the cancer patient. The use of chemotherapy with which our specialty is typically identified is often only a small part of the cancer care package. Effective cancer care requires the input of many dedicated individuals who make up the cancer care team. This team is in a unique position to favorably influence care of the cancer patient during the terminal stages of the disease. Unfortunately, excellence in care at the end-of-life is not routinely found in cancer care. More often, *inadequate* better

describes such care for the cancer patient.

The purpose of this text is to provide a guide for further development of skills that will enhance the role of the medical oncologist in end-of-life care encourage application of those skills earlier in the patient's clinical course.

INADEQUACY OF END-OF-LIFE CARE FOR THE CANCER PATIENT

The inadequacy of end-of-life care in this country has been documented in detail, both in the medical literature as well as in the lay press. More and more the general public is aware that the time of dying may also be a time of unrelieved pain and suffering. Clearly, the medical profession has a major responsibility for assuring that excellent care at end-of-life is the norm rather than the exception. Although end-of-life care is not exclusively a medical issue, it is clear that medical professionals are in a position to make major improvements in this area. As physicians we receive low marks in many if not most areas of end-of-life care including pain and symptom control, attention to spiritual needs, and our treatment of ethical issues. We do little better with management of other end-of-life symptoms such as dyspnea, nausea and vomiting and delirium. We often come up short when our patients need us most—at the end-of-life. Our training programs and even our basic motivations have been called into question because of the woeful statistics about terminally ill patients dying in pain.

INCREASING INTEREST IN IMPROVING END-OF-LIFE CARE

In recent years there has been a notable increase in interest in end-of-life care by medical organizations; this has been driven, in part, by examples of poor care of dying patients as described in newspaper and magazines articles. In our own literature the findings of the SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments) study document many of the unmet needs of the dying (SUPPORT, 1995). This extensive project received $28 million in support from the Robert Wood Johnson Foundation over a five-year period.

SUPPORT STUDY

4,301 patients: observational phase (Phase 1)

4,804 patients: interventional phase (Phase 2)

50 percent died within six months of entry into SUPPORT

The investigators in the SUPPORT study surveyed 4,301 patients during a two-year observational phase and an additional 4,804 patients during a two-year interventional phase. Part one of the study documented the communication deficiencies surrounding end-of-life care decisions of hospitalized patients. In particular, the communication issues left unaddressed until so late in life are underlined in this important study. Only 47 percent of physicians surveyed in this study knew when their patients preferred to avoid CPR. Most of the CPR orders (46%) were written during the last two days of the patient's life. Subsequent observations in this area clearly indicate that patients wish to discuss their physical symptoms with their physicians, but few do so (Steinhauser et al., 2000).

SUPPORT Phase 1 Observations

Only 47 percent of physicians aware of DNR preferences

46 percent of DNR orders written during last two days of life

50 percent of patients had moderate-severe pain in last three days of life

Inadequate pain management was also noted in this study; 50 percent of conscious patients dying in-hospital experienced severe pain at least half of the time.