

Cancer Treatment and Research

Steven T. Rosen, M.D., Series Editor

Robert H. Lurie Comprehensive Cancer Center
Northwestern University Medical School

**Ethical Issues in
Cancer Patient Care
Second Edition**

edited by
Peter Angelos

 Springer

**ETHICAL ISSUES
IN CANCER PATIENT CARE
SECOND EDITION**

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Steven T. Rosen, M.D., *Series Editor*

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edited by

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Clinical Medical Ethics
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 Springer

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For Meghan, Christian, Audrey, and especially Grace

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INTRODUCTION

Peter Angelos

Numerous ethical issues arise in the care of oncology patients. Although much has been written in the last several decades on ethical issues in caring for patients, few volumes have sought to focus the exploration on ethical issues particularly relevant to the care of cancer patients. In 1999, the first edition of this book was published. Since that time, many changes have occurred in how some cancers are diagnosed and treated, but the central ethical issues have continued to challenge patients, families, and their health care providers.

All of the chapters from the prior edition have been updated and there are seven new chapters in this expanded edition. In this second edition, the perspectives on what is an ethical issue have been broadened by bringing authors of differing backgrounds into the discussion. In Chapter 1, the perspective of a cancer patient is provided as an open letter to physicians. Although Parvez Kamangar is providing only one patient's perspective, this is an essential voice that is not often heard in texts on medical ethics.

In Chapters 2 and 3, the issues of communication and the physician-patient relationship are explored in order to better understand how the needs of patients and families can be met. In Chapter 4, Professor Tod Chambers highlights the challenges to providing ethical care to patients in a multicultural society.

In Chapter 5, the issue of "hope" is explored by a social worker with an extensive background in helping cancer patients manage their hopes and expectations in the course of living with cancer. In Chapter 6, Christina M. Puchalski explores how the spiritual needs of patients can be appreciated and addressed. In Chapter 7, the specific ethical issues of pediatric cancer patient care

are explored. In Chapter 8, Professor Timothy F. Murphy examines the ethical issues associated with responding to the pain and suffering of patients.

Chapters 9, 10, and 11 explore different aspects of oncology care near the ends of life. The difficult concept of “futility” is explored first. Subsequently issues in palliative medicine are considered for both adults and children.

In the remaining three chapters, specific important aspects of caring for cancer patients are raised. In Chapter 13, the issue of how to communicate about errors is addressed. As cancer patient care becomes increasingly complex, errors inevitably occur and an ethical approach to communicating about them is needed. In Chapter 14, the important role of clinical trials in oncology care is discussed. Since many patients participate in, or at least consider entering, a clinical trial, this aspect of oncology care cannot be ignored. In the final chapter, potential financial motives for decision making are considered in an attempt to better understand how such factors might influence the care of cancer patients.

The goals of this volume are multiple. First, to raise the awareness of doctors, nurses, and other members of the health care team to the important ethical issues that must be addressed in providing medical care to cancer patients. Second, to influence caregivers to think about how to be better prepared to address such issues when they inevitably arise. Finally, to encourage members of the health care team to take the ethical issues seriously so that we can improve the circumstances of a vulnerable group of patients—those with cancer.

1 AN OPEN LETTER TO DOCTORS*

Parvez Kamangar

The subject of “Ethics in Medical Care” is a subject very close to my heart. I started “The Humanity in Surgery Lectureship” in 1997 at Northwest Society of Colon and Rectal Surgeons. I am forever grateful to this fine organization to allow a cancer patient to take part in their annual meeting for the first time and perhaps open a small window into the mind and soul of their most valuable assets...their patients. These lectures are still continuing.

Later in 2003, I was very honored when “The American Society of Colon and Rectal Surgeons” (the “ASCRS”) allowed me to start a National Lectureship in the annual meetings. My invited guests have brought the subject of ethics and the humane treatment of critically ill patients to the forefront of discussion and debate. All members are in total agreement that this subject is too important to be ignored. In a 5-day meeting packed with hundreds of scientific subjects, a mere 30 minutes can be found to remember ethics.

*Editor’s Note: Mr. Parvez Kamangar is a successful businessman who has funded an annual Humanities in Surgery lectureship at the American Society of Colon and Rectal Surgeons meeting. Mr. Kamangar is also a cancer survivor. I have asked him to write an open letter to doctors about his experiences. Note that for a patient, the experience of illness is always personal—unlike the situation for health care providers who can generalize. Mr. Kamangar’s unquestioned acceptance of his gastroenterologist’s recommendations led to his subsequent intense feeling of betrayal. We should pay particular attention to the details of the experience that are so memorable to this patient, but are not always emphasized by health care providers. Despite some very critical things Mr. Kamangar states about physicians, he has taken both his positive and his negative experiences with doctors as an incentive to try to improve the ethical care of patients.

In this process, they have enriched my life and have rewarded me with their sincere concern for *treating the patient as well as treating the illness*.

I have found with undiluted pleasure and surprise that some of the finest human beings I've ever met are in your noble profession, and that should give all of us patients room for hope and improvements. The anatomy of my illness and the history of this lectureship are closely connected and may be of interest to you.

Here is a very brief version....

Prior to 1993, I had never had a major health problem. I was a healthy 52 year old white male workaholic. I had stress at work, but who doesn't?

No history of cancer in my family. Cancer did not enter into my wildest imagination. You only see those things in the news.

In the spring of that year, I did not feel well. Nothing specific. Just not well. I was tired...did not enjoy doing the things I used to...stopped socializing and stayed home more often. My appetite was not the same. I got irritated more often.

I should have gone to my primary doctor, but put it off thinking, *it was just a phase I'm going through*.

By June of that year I was getting worse...my digestive system was messed up; more importantly, I was bleeding. I knew then it was time to go to the doctor.

My primary doctor was very concerned. I saw the fear in his eyes. He did not even want to examine me. He sent me straight to a specialist. It was much later that I realized my primary doctor was a great doctor, but unfortunately not a good judge of specialists!

My gastroenterologist was in the same building. After a brief discussion, he assured me that I had nothing to fear...most likely I had a parasite!!! He gave me some pills to take and told me to keep in touch.

This was the beginning of my problems. This is where I wished that I had known better.

My symptoms got worse. I went back to see him and complained. He started by asking me if I had traveled to any exotic destination: South America? China? Etc. When I answered "yes", he thought he had it all figured out. *Another pill!!!* During the entire

period, there was no discussion of colonoscopy, colon cancer, or any other internal difficulties.

When I brought up the subject of cancer, he assured me that I should not worry about such things!!! My third prescription consisted of 30 cure-all mega tablets...one a day for 30 days. Although painful with some side effects, they will cure anything and everything, even if it is from China. While this was going on, my colon cancer had entered stage III and was progressing. My bleeding more constant. No appetite. Abdominal pain. Diarrhea.

As I look back at those days, I ask myself how naïve could I have been? Where was my head? What was I thinking? Why didn't I take better control of my care? Why didn't I get a second opinion? As complicated as the answer may be, it is really simple. It goes back to the roots of my upbringing and my unquestionable respect for the medical profession. The doctor was knowledgeable, educated, and concerned. The doctor was someone I automatically looked up to and at times envied. A doctor would never do anything to hurt a patient.

So sad how times have changed. So sad that I no longer feel that way at all.

I could not finish the pills. I was really sick. I knew there was something wrong. Upon my insistence and only then, he agreed to do a colonoscopy.

During this procedure, unlike many others I have had since then, I was quiet, alert, and looking at the monitor. I could see everything. It did not look good. I knew right then this monster should have never been allowed into medical school.

In the recovery room (Waiting? Room) I was drinking the apple juice as the doctor walked in.

"You were right all along," he said. "We should have done a colonoscopy earlier. You do have colon cancer and it has progressed. It doesn't look too good." There was no emotion in his face, no compassion, no feeling, nothing. He was a monster. "We are going to send the samples to the lab for test and we will have the answers in a few days."

I was speechless. I was frozen to my seat. I was angry—not at my illness, but at my doctor. I had never known anyone (closely)

with cancer. No one in my family had ever had cancer. This was my first experience. Just like that, my life was over.

He and I never had much chemistry for each other. He was a large, overwhelming man. He never sat down...just stood there and looked down at me. He never took the time to ask me any questions. He never asked about my family. I tried hard to look into his eyes, but they were not there.

Ever since this experience, I've encouraged my friends and family to change doctors or to get second opinions if they didn't believe in the one they had, or disliked him/her from the start.

I had so many questions. I forced myself to ask him one. "What are my chances?" "Not good," he said. "You most likely need a colostomy."

Then I made a *big mistake* and asked, "What is colostomy?"

As he was leaving the room, he assured me that his secretary would give me the name of a few surgeons that could do my operation. There was no discussion of follow-up or any offer of help. It was very mechanical. He was a sick man; the entire medical profession should be ashamed of him.

I don't know the result of those tests. I never went back to that office. I still get angry—13 years later—driving around that neighborhood.

Somehow, I made it home. It was not easy. I didn't know what I should do next. My doctor did not give me any direction or guidance. I decided to call my friend, who is a doctor here in town. He was really very nice and understanding. "Sit still," he said. "I'll get back to you."

He called back. He had it all arranged for me to see a friend of his. A colon and rectal surgeon. The next two days somehow went by. Don't ask me how, but they did. I kept it all to myself. I did not share it with anyone. It was the worst two days of my life.

I entered the office of my new colon and rectal surgeon without much hope. No matter how hard I tried, I couldn't hide my feeling of hopelessness.

He was very pleasant. He listened, did a short exam, and had a long talk with me. Here I wish I could write well and explain the difference between these two doctors.

This surgeon was a great human being before anything else. He expressed his disappointment about how I had been treated. He emphasized the importance of putting my first doctor out of my mind for the time being and to look forward to positive things. “You cannot afford to be angry. Cancer is not a death certificate,” he said. “Many forms of cancer can be treated, controlled, managed, and cured.”

My surgeon said that if I was willing to go through the difficulties ahead, he would put together a team that will fight for me and with me. One thing that I will never forget is how this doctor was concerned about how many days of work I was going to miss after my operation! He assured me that if this was a big problem, he could arrange for a private telephone and fax machine in my room!

He wanted me to be strong and optimistic. He had heard from our mutual friend that I had had many challenges in the course of my business. This was “no different,” he said. “Just another challenge...this time we are here to help you.”

I asked him about colostomy. “You do not need that,” he said. “A gastroenterologist is not qualified to make such a statement. That is the surgeon’s decision.”

I was shocked, angry, and happy all at the same time. *Could my first doctor be purposely trying to hurt me? Is he a psychopath? How is he still practicing medicine?*

We made arrangements for my operation. “Precious time has been lost; we have catching up to do.” He was careful not to give me any false promises or hope, but he emphasized the importance of being positive. I was so happy to meet someone that cared. I did not feel alone anymore. This man was born to be a doctor.

I left his office a totally different man. The highs and lows are not easy for me to describe. I wish I could. Perhaps you could share it with your students and some of your colleagues.

How can all this be possible?

Earlier that day, I had spoken with my trust attorney and asked him for an urgent meeting with him to go over my will and rewrite a few things...he was very understanding, expressed his sympathy, and arranged a time. I called him back that afternoon and cancelled. I was going to live.

The day of my operation started well. In the prep room I was greeted by a very nice lady with a big smile. My surgeon was there

when they rolled me into the operating room. He welcomed me and introduced me to everyone in the room who were busy making the last minute preparations.

I was very surprised and pleased to hear my first and last name pronounced correctly. Small details like that are important. It signifies the doctor's interest in his patient and in his profession. The atmosphere in the room was good. I had a feeling that everything was going to be just fine. I was determined to fight.

They started to hook me up with wires and needles. My surgeon explained to me what everyone's duty was and what he hoped to accomplish. He did this in language that I could understand...not in medical jargon.

I don't like blood or knives, so I was glad that he did not go into details. Then I counted to 10...

My recovery got a little complicated. I had to stay in the hospital a few days longer than expected. My surgeon assured me that the operation had gone well and he was even more hopeful than before. "These difficulties are not uncommon and they will pass." I believed him.

During those difficult days I learned some valuable lessons. First, I realized how underappreciated the nurses are, and how all of us—including doctors—should learn from them. My nurses were professional, kind, compassionate, and hardworking. They gave me hope and positive energy. During my most difficult night, my nurse stood by my bed, held my hand and assured me that what I was going through was expected, part of the operation, and would pass. She was right.

I also realized how important and valuable my family and friends were to me at such a difficult time. Their love and understanding healed my wounds. It really did. I felt as I had to recover and go home for them, if not for myself.

It was during this time that I also realized how imperfect medical science was. As patients, we expect perfect results and often we are disappointed. This was all so new to me. I did a lot of thinking in the hospital.

How imperfect is this profession?