

# Cancer Symptom Science

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Measurement, Mechanisms, and  
Management

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## Measurement, Mechanisms, and Management

Edited by

**Charles S. Cleeland**

**Michael J. Fisch**

**Adrian J. Dunn**



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## Foreword

...For the secret of the care of the patient is in caring for the patient.

Francis W. Peabody

*Cancer...Symptom...Science.* Simply reading the three words grouped together in the title of this book signals that we have indeed entered a new age in the way we will consider how to treat a person diagnosed with cancer. To those of us who have long advocated for integrative, evidence-based cancer care that recognizes, assesses, and then treats the whole person with cancer, this book is a welcome addition to the body of research that finally puts the biology of cancer in line with the real experiences of patients. And perhaps most importantly, this book now substantiates the case to all of us – health professionals, patients, and those who finance health care – for treating them accordingly. As this book so importantly points out, we now know how to measure the severity of symptoms that wreak havoc with a cancer patient's recovery and to examine what is happening biobehaviorally, even though it was not so long ago that this realm of research was relegated to an area of science considered to be “soft” and not easily quantifiable. Today, quality cancer care is ideally based not only on familiar, quantitative “hard” science, but on a marrying of the quantitative with the qualitative – the subjective experiences of people with cancer – to determine the best intervention for any one person or a population of people.

My own experiences with cancer have motivated my support of cancer-related and disability rights causes for more than 40 years, the last 20 of them at the National Coalition for Cancer Survivorship (NCCS). Nearly six years ago, I was invited to speak to a meeting of researchers interested in symptom management that was hosted by Dr. Charles Cleeland at The University of Texas M.D. Anderson Cancer Center. A long-time admirer of Dr. Cleeland's work, I did not hesitate to accept. As I considered how in 20

minutes or less to discuss my organization's strategy for making the treatment of cancer-related symptoms a health care priority for policymakers in Washington DC, I realized that I would have a friendly audience, and that the real challenge would be to ensure we had the evidence base that would allow us to take that message to our lawmakers and to those who determine what is valued in health care today.

My message 22 years ago, when I became an activist for quality cancer care, and my message six years ago, when I spoke to Dr. Cleeland's colleagues, are no different from what I am writing today. The difference is that we now have a contemporary body of evidence that can support the interventions needed to minimize the many domains of distress that often come with a diagnosis of cancer.

My own cancer survivorship began nearly four decades ago when on December 23, 1971, two events got my attention. One was very personal, and the other quite political. On that day, I began treatment for stage IV Hodgkin's lymphoma, and the news programs on television that night began with the announcement that President Richard Nixon had signed into law the National Cancer Act, officially declaring a “war on cancer.” On that day, I began my education about how we, as a nation, have made cancer a political issue, and how one individual with cancer, under the best of privileged circumstances, experiences our health care system when dealing with a life-limiting illness.

The 1970s were an era where a diagnosis of some common cancers in children was no longer an immediate death sentence, yet where pain and suffering for adults diagnosed with cancer was not uncommon, where outcomes for most adult cancers was virtually uncertain, and where most of the research on the psychosocial and behavioral aspects of cancer was concerned with whether or not to tell the diagnosis, how to prepare for death, how to manage bereavement, and generally, how to reduce suffering (that overly simplified snapshot of cancer care looks very different today).

Foreword

When I was diagnosed in 1971, I wanted to take part in a clinical trial that was testing some new combination of anticancer drugs, but I was considered ineligible because I was four weeks postpartum. Instead, I was treated with radiation alone, which at the time was not considered to be curative for my stage and type of disease. The cobalt 60 total nodal irradiation virtually rendered all who received it infertile – an outcome that was not discussed with me prior to my treatment, out of concern on the part of my doctors that I might defer or refuse the treatment. I lived for 12 years without a recurrence, but with lingering short-term and late effects of the radiation treatment, including early-onset menopause, infertility, radiation-induced pericarditis, costochondritis, and cardiac arrhythmia, precipitous deterioration of my lumbar and cervical spine, recurrent bladder inflammations, and a painful and somewhat debilitating chronic condition called avascular necrosis. In 1984, I had a recurrence and was treated with the very chemotherapy regimen that was tested in the 1971 clinical trial, but which left me with painful neuropathy in my feet and hands that persists to this day. That recurrence also left me with a level of apprehension that was only effectively managed with excellent psychotherapy and a short course of medication. In 2007, I was diagnosed with significant coronary vessel and valve damage, concluded to be consequential to radiation exposure, and then bilateral breast cancer, also most likely to be a late effect of prior treatment.

Today, I am thankfully cancer-free, but never will I be free of cancer or its consequences. My desire to be part of a clinical trial in 1971 and the inability to participate has made me an ardent advocate for quality cancer care, with a special respect for the clinical trials process as a way of advancing new therapies for people diagnosed with cancer. I have carried out my work as an advocate over the last two decades working for the National Coalition for Cancer Survivorship. For nearly 25 years, NCCS has been at the forefront of the cancer survivorship movement – a movement that today includes scores of cancer survivor-led information, support, and advocacy organizations. The survivorship movement did not exist prior to the founding of NCCS. The founders included a public health physician, oncology professionals (including oncology nurses and social workers), experts in disability law, insurance reform, psychosocial research, and biomedical research, and cancer survivors who had led peer-support groups in their communities. Together, they

created a new language for cancer, beginning with defining the word “survivor” as anyone with a history of cancer – from the moment of diagnosis and for the remainder of life. The founders of NCCS were expansive in their approach to using this new language, by including in their definition of “survivor” a cancer patient’s family, friends, and anyone who supports the person with cancer – recognizing the devastating effect this diagnosis has on everyone involved in the life of an individual undergoing cancer treatment.

Nearly all of us diagnosed with cancer will tell you that it affects us on a physical, emotional, social, economic, and spiritual level. With some exceptions, cancer survivors are eager to tell you their stories and all of the health professionals who work with cancer survivors know that learning from their patients’ experiences can provide insights into the true nature of illness and how individuals experience it. At NCCS, we know that being an informed and empowered consumer, as well as finding ways to improve the quality of one’s life while being treated for cancer, can make a tremendous difference in how well or how poorly an individual adjusts to a diagnosis of cancer. Communicating with others about our hopes and fears as well as about how our family relationships and functioning have been affected by cancer is very important. For many survivors, reaching out to others – whether seeking psychosocial support from individual professionals or participating in support groups in person, over the Internet, and over the telephone – is key, and many have found hope by listening to and sharing with others their own stories of survivorship.

I am a privileged cancer survivor. Through all of my cancer and related health issues, I experienced them under the best circumstances. I have often considered over the last four decades what would have happened if I had not been living in the Washington metropolitan area where access to quality cancer care was so readily available. What if I had not had adequate health insurance coverage or had been underinsured? What if I had not had a supportive employer? What if I had been raised by a family that viewed my cancer diagnosis as a shameful event that put a curse on our household, as some survivors have told me was their experience? What if my spouse had not been able to cope with my difficulties reentering our family life, as so often is the case with less fortunate survivors?

To answer some of these questions as they apply more generally, we turn to the policies and politics of cancer. Those of us whose work is found in

cancer-related advocacy have a rich history of involvement that has informed cancer policy. Starting with the grassroots, from 1992 to 1994 NCCS held a series of talks in Town Halls in cities across America to listen and learn from people living in diverse communities about how they were experiencing cancer, with a special interest in how their quality of care and quality of life were having an impact on their daily living. Taking what we learned from these Town Halls, and wanting to bring together many of the community leaders we met in our travels, NCCS assembled the broader cancer community in 1995 by convening the First National Congress on Cancer Survivorship. This three-day Congress was our effort to bring what we had heard from ordinary people to the attention of a broader audience in Washington DC and to work with them to come up with a set of essential elements for quality cancer care. The consensus findings and recommendations from this assembly were published by NCCS in our *Imperatives for Quality Cancer Care*.<sup>1</sup> These Imperatives for the first time defined quality cancer care in a written document, with recommendations that were informed by the patients’ perspectives. The Imperatives call for treating the whole person with cancer, with a multidisciplinary team of care providers across the full continuum of care. The National Cancer Institute responded to the recommendations in the Imperatives by establishing the Office of Cancer Survivorship in 1996 and by making one of the authors of the Imperatives, Dr. Julia Rowland, director of this office. Two of the key principles outlined in the Imperatives:

- People with cancer should be provided with a range of benefits by all health care plans, including primary and secondary prevention, early detection, initial treatment, supportive therapies to manage pain, nausea, fatigue and infections, long-term follow-up, psychosocial services, palliative care, hospice care, and bereavement counseling.
  - The provision of psychosocial services must be safeguarded and promoted. Persons diagnosed with cancer should receive psychosocial assessments at critical junctures along the continuum of cancer care to determine availability of needed support and their ability to seek information and to advocate on their own behalf.
- These principles are part of the best practices used by many oncology professionals today in treating people with cancer. As further evidence in support of these interventions, in 1999 the Institute of Medicine

(IOM) researched and published the first in a decade-long series of reports, beginning with *Ensuring Quality Cancer Care*,<sup>2</sup> that cited these principles as integral to the provision of quality cancer care. What cancer survivors experience – the qualitative, anecdotal, day-to-day living with and dying from this disease – does not always find its way into the research, because the dollars to adequately fund it simply haven’t been allocated. Subsequent reports issued by the IOM have given us a robust body of additional evidence for how much this research is needed and that we will, in the not too distant future, be able to proudly point out how much the interventions addressed in *Cancer Symptom Science* will truly help people with cancer live better lives and, when the time comes, have better deaths.

Over the years of my survivorship, I have read many beautifully expressed stories of extraordinary people who live their survivorship and their dying with grace and dignity. One story in particular is vividly etched in my memory. It was written in an essay entitled “Under Toad Days” by physician and cancer survivor Elizabeth McKinley.<sup>3</sup>

After my very last radiation treatment for cancer, I lay on a cold steel table, hairless, half-dressed, and astonished by the tears streaming down my face. I thought I would feel happy about finally reaching the end of treatment, but instead, I was sobbing. At the time, I wasn’t sure what emotions I was feeling. Looking back, I think I cried because this body had so bravely made it through 18 months of surgery, chemotherapy, and radiation. Ironically, I also cried because I would not be coming back to that familiar table where I had been comforted and encouraged. Instead of joyous, I felt lonely, abandoned, and terrified. This was the rocky beginning of cancer survivorship for me.

I’m DONE, according to the medical profession. But I don’t really FEEL done. I think we survivors are never truly done. We just move from the quantifiable, treatable disease to the immeasurable uncertainty of survivorship. Being in the midst of active treatment means being seen regularly by a nurse or a physician – being truly CARED for. As I got up off that radiation table for the last time and walked away, I found myself alone with a cancer ghost who would not let me forget where I had been or allow me to freely choose where I might be going.

Foreword

We cancer survivors are millions strong, and our ranks will continue to grow as improved cancer treatments extend our lives. But because this struggle with uncertainty after treatment is completed is usually a silent battle waged outside of the physician’s office, most physicians don’t think or talk about it. In my life as a primary care physician before cancer, I certainly did not. Now I believe that we physicians need to talk with our cancer survivors about the unique struggles of survivorship. Oncologists need to focus on preparing us cancer patients for survivorship. That is, they must address the loss experienced by survivors when active treatment is over and they are sent away from a very intense environment. They must help survivors understand the impact of fear and uncertainty on their lives and what might help to reduce these stresses.

For Dr. McKinley and millions of others, some of the questions we have left to explore include, but are not limited to, the following:

- What are the most common short-term and late effects of cancer treatment and who is at risk for developing them?
- Are there ways to evaluate who might be at highest risk for these effects and can they be prevented or minimized?
- What is the best way to follow cancer survivors for late effects of treatment, and to monitor for recurrence in those at highest risk?
- What are the costs of providing this follow-up care?
- Do behavioral or psychosocial interventions reduce physical or other morbidities in these populations?

The book you hold in your hands begins to address some of these questions, combining the work of basic and clinical scientists, whose research can often be neatly quantified and measured, with the work of behavioral scientists, whose research is often based on subjective patient report – all to create this new discipline called symptom research. Here we can learn about the true science of biobehavioral research that takes a deeper dive into our understanding of how we can better manage many of the consequences of a cancer diagnosis. The important work of this interdisciplinary symptom-research community tells the story of thousands of my fellow survivors who have become

part of a documented history of cancer survivorship. This work tells the very human stories of the way people with cancer cope with the distressing symptoms – the physiological and psychosocial consequences that people experience as they live with and, sadly, die from cancer. We survivors know how this work can be measured; we know how valuable it is; and we also know that it needs to be valued by those who pay for health care, and by the health professionals who deliver that care.

When I first began to advocate for quality care for people with cancer, a colleague sent me a paper by Dr. Stanley Reiser, published in *JAMA* and titled “The Era of the Patient,” in which he wrote about using the experience of illness in shaping the mission of health care.<sup>4</sup> He referenced an article quoting Václav Havel’s views of the politics of the world. He cited Havel’s critique and its similarities to science and medicine’s continual evolution and development. Havel wrote:

Things must once more be given a chance to present themselves as they are, to be perceived in their individuality. We must see the pluralism of the world and not bind it by seeking common denominators or reducing everything to a single common equation. We must try harder to understand than to explain. The way forward is not in the mere construction of universal systemic solutions, to be applied to reality from the outside; it is also in seeking to get to the heart of reality through personal experience.

Over many decades, cancer survivors have discussed their fears and their hopes, their feelings of anxiety and uncertainty, with many in the health professions. They have reported their symptoms to their oncologists, to their nurses, social workers, and others – only too frequently to be undertreated. Thankfully, with the publishing of this book, we have reason to hope that quality care for people with cancer will truly be integrative and leave no patient without proper symptom management throughout their survivorship – from the moment of diagnosis and for the remainder of life – for after all, it is the quality of living that we seek to preserve.

Cancer survivor and author Arthur Frank, in his book *At the Will of the Body: Reflections on Illness*,<sup>5</sup> put it this way:

I am trying, in this third year after cancer, to be a little less afraid. Some days the world seems immensely fearful...and I realize that the only real difference between people is not health or illness, but the way each holds onto a sense of value in life. When I feel I have no time to walk out and watch the sunlight, my recovery has gone too far. A little fear is all right. It is all right to know that in a month I could be lying in a hospital bed asking myself how I spent today. Holding onto that question – how did you spend today? – reminds me to feel and see and hear. When the ordinary becomes frustrating, I have to remember those times when the ordinary was forbidden to me. Now that I am back in the ordinary, I have to retain a sense of wonder at being here.

Ellen Stovall, April 2010

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It has taken an extraordinary amount of time for the book to find its way into print. First, cancer symptom science is a developing area of investigation, and the collective knowledge base for the field is dynamic and rapidly evolving. This has led to course corrections along the way. Second, we have engaged a highly heterogeneous group of very busy clinical and laboratory investigators who often had to do some background preparation by learning about complementary research areas before they could make a contribution to this very multidisciplinary book. We thank them for this extra effort. Certainly the editors have learned much in this process, and we hope that the contributors have gained from it as well.

One consequence of this delay is that it potentially detracts from those who got their contributions in on schedule, as both their own and others' research may

have moved on to provide information not included in these chapters. The laggards and procrastinators have benefited by having a more up-to-date look at their topic. This problem is easily remedied: a quick literature search by the authors' names should bring you up to date.

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Finally, we would like to note, in memoriam, those of the editors' families who have died of cancer and have suffered the symptoms that this book addresses – Abby, Linda, Joseph, Gus, and Louis Doctor; John Charles Dunn; E. M. and Martha Helen Flake; and Eclas Houston Patterson. Were we able to include the names of all the family members of the contributors to this book who have suffered, and possibly died, from cancer and its effects, this remembrance would likely fill a page.

It is to them, whether known to us by name or not, that we dedicate this work.