The Psychological Impact of Acute and Chronic Illness: A Practical Guide for Primary Care Physicians

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This book is dedicated to all of the patients who have taught me, through their courageous struggles with illness, about the impact and meaning of the diseases that plague us.

T. M. G.

FOREWORD

In the following pages, Dr. Greenberg delineates the complex forces at play within patients who are newly ill or disabled, within physicians who do their best to guide patients through those debilities, and in the interaction that patient–physician dyads perform thousands of times daily to try to make sense of the patient's plight.

As a physician and medical educator who thinks about how to enhance communication between patients and physicians, I often view communication challenges as arising from divergent cultural experiences. Each patient has a unique method of experiencing, deriving meaning from, and coping with a new or chronic illness. This approach is necessarily filtered through the patient's family and social contexts and the patient's current living situation.

Physicians, too, bring psychosocial upbringing and current social context into their clinical practice settings. We have also been inculcated into a medical culture that takes its bright, impressionable, idealistic young and shapes them, sometimes brutally, into diagnosticians and proceduralists. We are just now beginning to understand the many components of the "hidden curriculum" of many medical schools – unspoken but powerful influences in training that undercut the humanity of trainees and turn them into poorer communicators than when they first started.

The challenge is to achieve and prioritize connection, both in medical education and in practice. Many of my procedure-based colleagues achieve

this nonverbally, by fixing a problem, and many patients deeply appreciate their outcomes. An equally powerful connection forms through empathic witnessing of a patient's situation, even if we cannot fully understand all that a patient might be undergoing. In addition, research suggests that the presence of an empathic statement in both medical and surgical settings can *decrease* the length of an outpatient encounter. Presumably, as clinicians share that they understand what a patient might be undergoing, the patient leaves more satisfied. This outcome is clearly desirable for patients, physicians, and health care systems.

The other day, I saw Mr. A, elderly in years but still sprightly. When I first met him, about four years ago, I found his communication style somewhat challenging. He would flit from subject to subject, most of which were nonmedical and which I deemed unimportant. He told me about classes he took at the local community college on spirituality and love. He told me of his son, his divorce, and continuing loving relationship with his ex-wife, his present friendships, and his continued sexual escapades, both consensual and individual. He showed me photos of his artwork and of himself when he was younger. Each time he left the office, I knew I was missing his point: somehow he was trying to tell me something, but I was too dense, too distracted, and mostly too uninterested to figure it out. Anyway, it was onward immediately to the next patient, so I never stopped to think about it.

Over time he had to have a total knee replacement, then a coronary bypass, and, most recently, urgent surgery for a humeral fracture suffered in a fall. Through these major procedures, Mr. A was sunny, upbeat, and completely (and a bit maddeningly) insistent on continuing to tell me tangential stories.

So when I saw him on my schedule the other day, I was expecting more of the same. Instead, in walked a rather dour man dressed in gray and black, when I'd come to expect vibrant multiple colors. At once I knew that Mr. A had reached the limits of his substantial coping ability. Three successive surgical procedures and rehabilitation processes had finally taken their toll. He could neither walk nor lift his dominant arm without pain, and he began to despair that he would never regain full function. He'd stopped his numerous activities, was eating and sleeping poorly, clearly had low energy, and could not concentrate. Though he vehemently denied suicidal ideation. When I asked him, "Do you have any guilt?", he instantly

became tearful. He spoke of how he was re-evaluating his life and felt that he'd been terribly selfish with his ex-wife; maybe if he'd treated her better, they'd still be together. The loneliness was palpable. Now I understood the numerous activities and the flitting about better: they masked his pain.

In diagnostician mode, I'd uncovered his obvious major depression (or was it a bit of bipolarity? Maybe a bit of histrionic personality style mixed in?). But it finally became obvious why he'd told me so many stories that I'd previously discounted as irrelevant. He was telling me who he was. He'd given me an extraordinary gift of letting me into his life, not just the compartmentalized medical stuff, but how his illnesses related to him, Mr. A, the *person*, not the organism. In response, I'd left his gift unopened on my stoop, wondering if it would go away.

Now that I could understand more about my own resistance to Mr. A's stories, I found myself more fully appreciating him. As a doctor I often feel compelled, as Dr. Greenberg notes in Chapter 2, to action. Though Mr. A and I went through the obligatory discussion about antidepressants (see Chapter 5), I felt an important need just to be in the same space as he. Somewhere, deep inside, I was saying to myself, "Don't just do something, be there."

By the end of the visit, Mr. A felt compelled to quote a poem of Edna St. Vincent Millay called 'Love Is Not All.' Though I'm generally not a "poetry person," by his ability to reach through his depression into himself and share a piece of his passion with me, I knew that my low-tech intervention of empathic witnessing had succeeded.

Calvin Chou, MD, PhD
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FOREWORD

This is a particularly challenging time in medicine. While our scientific knowledge is rapidly expanding, both patient and clinician satisfaction with our health care system is declining. Students enter medical school with strong humanistic and ethical ideals. Over the four years, they assimilate more knowledge than they knew possible. They are then faced with several years of residency when they must continue to acquire knowledge and skills while providing direct patient care. Given the enormity of this task, our education and health care systems encourage a primary focus on the traditional, evidence-based science of medicine. The psychology of illness is either assumed to be self-evident or is left to the purview of mental health professionals. This is not a realistic approach and not what most of us desire from our physicians.

As individuals, nobody teaches us how to think about and respond to illness. Although virtually all medical schools now teach some form of the psychology of illness, most students attend first to the "hard" science courses, fitting in the "less scientific" courses as time permits. Residents quickly learn the frustration that comes from dealing only with the illness when they see Mrs. Smith back for her ninth admission in three months with the exact same symptoms. It's as though they have the know-how to pull a car out of a skid, can tell people in detail how to respond, and then have to watch person after person go into a skid. Clearly, something more is needed.

Dr. Greenberg examines the history of illness and psychology, giving the reader a context for current beliefs and practices in Western medicine. It is generally acknowledged that certain illnesses, like asthma, have a psychosomatic component. Unfortunately, many people think this means the illness is in the sufferer's head, that the symptoms are not real. Studies clearly show that mood state affects the outcome of a variety of illnesses, like coronary artery disease. Most physicians continue to focus on the hard facts: tests, treatments, etc. Most patients, however, care most about their ability to function and engage in their lives.

Bringing her years of work as an astute and respected clinician, educator, and colleague, Dr. Greenberg demystifies patients' psychological needs, giving the reader an understanding of and an approach to caring for the entire patient. We all have different coping strategies, roles, relationships, and predisposition to mental illness that are brought to bear in dealing with illness, which is among the most stressful tasks of living. As clinicians, we interact with the illness and the patient before us, as well as with their entire history, family, culture, and level of trust of the medical establishment. Although referral to a mental health practitioner in conjunction with ongoing primary care is sometimes the answer, it is neither possible nor desirable in all instances. Dr. Greenberg demonstrates the synthesis of medical and psychological approaches into a coherent treatment approach.

This wonderful book is a must-read for all clinicians. Use it repeatedly as a reference; both you and your patients will benefit greatly.

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PREFACE

Medicine is a rapidly changing field. The many variables in the practice of modern medicine—the influence of technology on medicine, HMOs, the complicated psychological dynamics that patients bring to physicians, the changes in pharmacological treatments for mental disorders, and family dynamics and interactions—all make the practice of medicine difficult and complicated. The demands on physicians are unprecedented. Patient expectations are increasing and, as the population ages, are likely only to continue to increase. These changes will probably intensify the demands placed on physicians. Changes in the population of patients seen in today's medical offices require an increase in flexibility, as well as sensitivity, which makes the practice of medicine more interesting, and also more demanding, than ever before. I hope that this book can help ease the burden on physicians.

The purpose of this book is to help clinicians understand the normative as well as maladaptive reactions to illness. It is intended for primary care physicians, who as front-line clinicians provide the majority of medical as well as mental health treatments for a large number of patients in the general population. Specialist physicians may also benefit from the explanations provided in this book on the psychological dynamics of illness, as they, too, are confronted with patients for whom coping with illness is a major factor in treatment. Providers of psychological services who deal with medical patients may also find this book useful because it normalizes a lot of the issues in medical patients that some mental health clinicians may be tempted to pathologize.

One of the major changes in the current practice of medicine is related to the work of primary care physicians as mental health practitioners. Primary care clinicians prescribe more antidepressants than any other prescribers, and the field of psychotropic medication has changed and expanded in recent years with an increasing array of medication choices for patients with anxiety and depression. Chapter 5 attempts to decode many of the issues that primary physicians face when prescribing antidepressants and anxiolytics for patients and to address the potential pitfalls (i.e., medication interactions) that can occur when prescribing for patients with medical problems. Although physicians can pharmacologically treat a number of mental health problems, the need for a mental health presence with medical patients is increasing. Yet many physicians feel confused about how to refer patients for mental health treatment. Chapter 9 should help reduce the difficulty many physicians face when trying to refer patients for mental health treatment. Other chapters in this book are designed to help physicians understand the complicated and sometimes confusing reactions (e.g., helplessness or noncompliance) patients and their families have in response to serious illness.

I see patients in acute hospital settings and nursing homes, as well as in my outpatient private practice. I have been fortunate to work with the University of California, San Francisco, medical hospitals and clinics since 1997. This work started with a cardiothoracic surgeon, David Jablons, MD; I saw patients with thoracic malignancies in an outpatient clinic. I then began seeing patients who had a variety of physical disorders in Mt. Zion Hospital and then in the UCSF hospitals. Today I tend to see a limited number of hospital patients and continue to have relationships with certain UCSF faculty practice groups and to provide pre- and postoperative evaluations, pretransplant evaluations, and ongoing treatment for medical patients. I also have been fortunate to work with medical students in the UCSF Medical School, who continually educate me regarding the rigors of medical education and practice.

There are a number of colleagues who generously offered their time and expertise to read chapters and provide feedback regarding the concepts discussed in this book. Thanks to Greg Berman, MD; Peter Carnachan, PhD; Bart Magee, PhD; Kathleen Regan, MSN, NP; Anne O'Crowley, PhD; Annie Sweetnam, PhD; Maxine Papadakis, MD; Michael Guy Thompson, PhD; and Steve Tulkin, PhD, MS.

I am thankful to Rob Albano, my senior editor at Springer, who helped me translate the initial ideas for this book into a practical form and to clarify how this book might be most useful for physicians. I also appreciate the wisdom of Merry Post, my developmental editor, who patiently helped to make my writing more readable.

I am especially grateful for the help of Andrew McClintock Greenberg, MD, PhD, my husband and colleague, whose expertise of research methodology and clinical applications of research proved an invaluable resource in interpreting research. He was also a tireless editor and was gracious in offering his time to read and comment on chapter revisions. Perhaps even more valuable, Andrew was able to offer the clinician's perspective on the realities of patient care and medical practice in today's complicated world.

I am indebted to the patients who over the years have influenced my thinking about psychological responses to illness. It is through their courage, honesty, and insights that I developed a real and nonacademic understanding of the impact of acute and chronic illness. It is ultimately for them that this book was written, and it would have been impossible without their trust in me as a clinician. Though all cases in this book are based on actual patient encounters, identifying information has been altered to protect confidentiality and disguise identity.

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MEDICAL ILLNESS: WHY CONSIDER EMOTIONAL FACTORS?

"It is more important to know what kind of patient has the disease than what kind of disease the patient has."

—Sir William Olser

The interaction of the mind and the body has been of interest to many physicians, philosophers, and more recently psychologists, for hundreds of years. In recent years there has been increasing interest regarding how emotional factors, which include some psychiatric illnesses, coping skills, emotional states, and personality traits, impact physical health. Research regarding emotional factors and illness has demonstrated powerful links between the mind and the body. This chapter will review selected medical and psychological research in this area and will discuss possible mechanisms to explain these associations.

Medical and psychological researchers and clinicians have long known that psychological problems can manifest themselves physically (e.g., through psychosomatic disorders). More recently, there has been an increased understanding that not only is the impact of emotional coping important in persons who are already ill, but also that emotional states (including depression, anxiety, and hostility) are associated with the development of certain illness. Although the culture of Western medicine (which will be discussed further in Chapter 2) has taught us that the mind and the body

are separate, there is mounting evidence that the mind and body are symbiotic and that strong interactions between the two exist.

There are two important general areas of research related to interactions between emotional and physical functioning. The first area deals with certain emotional states and their role in the development or exacerbation of certain illnesses. The second major area I will address is the impact of coping on illness. The discussion on coping will deal with day-to-day responses to stressful events, attitudes, perceptions, and the use of religion and social support. Although there are certainly similarities between emotional states and coping, the coping research tends to focus on responses of persons assessed to be psychologically (and sometimes physically) healthy. Another interesting distinction between these two areas of concentration is that the research on emotional states and illness is often found in major medical journals. The research on coping is found more often in psychological journals. This difference may reflect differences in the fields of medicine and psychology in terms of what is regarded as "clinically significant" research. Further, the research on coping often addresses the impact of thoughts and attitudes that are present in most of us. The subjects of research on emotional states, in contrast, tend to be persons with difficulty in coping and resulting depression or intense anxiety. Additionally, the research on emotions focuses on personality traits such as hostility, cynicism, and mistrust that are not related to coping per se, but dramatically impact psychological processes. After presenting the research on emotional states and coping, I will discuss areas of research that do not seem to fit the category of either emotional states or coping. These areas include the large volume of research on stress, racial and economic disparities in health care, and the impact of child abuse on physical functioning.

DEPRESSION

Most, if not all, health care providers are aware of the high incidence of depression. Recent statistics from the American Psychological Association report that in the United States depression occurs in one out of five women and in about one out of ten men at some point in the lifespan.[1] Because of its prevalence, depression is thought by many to be a major cause of disability worldwide for both young and older adults.

Medical patients are more likely to be depressed than persons without chronic medical conditions, and the number of chronic medical conditions is positively correlated with an increased risk of depression.[2] Professionals in primary care settings so routinely encounter depression that screening for depression has become a regular part of most medical practices. Additionally, primary care physicians provide more pharmacological treatment for depression than any other medical provider and are most often the first provider of any kind to diagnose depression. However, information on how depression is implicated in the development and exacerbation of illness is still relatively new to many physicians because this research did not gain momentum until the mid-1990s.

Perhaps the most replicated and striking research related to depression and the development of medical problems is that depression has been found to play a role in the development of cardiovascular disease. Depression has been found to predict some forms of heart disease, which is the leading cause of death in the United States. Some of the earlier research in this area found that in persons who had pre-existing heart disease, depression predicted a poorer prognosis. For example, depression was found to independently predict a second myocardial infarction (MI) in patients who have already had a myocardial infarction.[3] Additionally, depression also predicts poorer survival among patients with coronary artery disease (CAD) and congestive heart failure (CHF).[4,5] Although much of the depression/heart disease research has suggested that people who are already ill and depressed live shorter lifespans, there is also evidence that major depression and depressive symptoms are associated with a first MI.[6–8] Although so far I have been describing research in which subjects were diagnosed with major depressive disorder (in most cases based on *Diagnostic and Statistical Manual of Mental Disorders* criteria), even persons who have a few symptoms of depression (minimal depressive symptoms as measured by the Beck Depression Inventory) and do not meet criteria for major depressive disorder are at increased risk for a subsequent myocardial infarction if they already have heart disease.[9] It should be mentioned that while earlier research focused primarily on men, due the increased prevalence of heart disease, similar findings have emerged in women.

Depression leads to poorer outcomes in both the elderly as well as medical inpatients. Patients who are both elderly and hospitalized are at greater risk of experiencing the negative impact of depression. Depression predicts

greater physical decline among the elderly. Among hospital inpatients with a variety of illnesses, depressed mood was an independent risk factor for mortality.[10,11] Some of the research on depression has assessed the risk of depression as compared with other risk factors. For example, a study of elderly women found that the risk of death due from depression was as significant as risks from smoking, high cholesterol, obesity, and diabetes.[12]

The research on depression and later development of cancer has yielded less consistent results than other research on depression and illness. Many confounding variables (e.g., the varying pathophysiology of different types of cancer, the effects of some cancers on the endocrine system, mood symptoms in response to chemotaxic agents, etc.) make studying associations between depression and cancer difficult. However, reviews of the literature and meta-analyses have found weak associations between depression and the development of cancer and slightly stronger associations between depression and the progression of cancer.[13–15] Additionally, although there have been inconsistent results, at least two studies have found associations between chronic depression and the development of breast cancer.[16,17] One difficulty in the cancer/depression research is that chronicity of depression is not always studied, and the measures of depression differ in many studies. A 2003 article by David Spiegel and Janine Giese-Davis, who are leading experts in this field, suggested that because of the inconsistent findings and methodological problems assessing depression in this patient population, there is only weak evidence linking depression and development of cancer, but that there is likely stronger evidence of an association between depression and cancer progression and shorter survival time.[18] These authors note, however, that the methodological problems such as not assessing chronic depression may obscure current interpretations of this research. Additionally, the physical effects of cancer can mimic neurovegetative signs of depression, thus further complicating the interpretation of research. Perhaps as more researchers study chronic depression, which could potentially cause alterations in immune functioning over time, we will have a clearer understanding of a depression and cancer association.

Emerging research links depression and loss of bone density. Studies indicate that in both young and perimenopausal women, depression is associated with an increased risk of osteoporosis.[19,20] One of these studies found an increased risk of bone density loss in women with both depression and borderline personality disorder.[20] There is also evidence that depression is also associated with decreased bone mineral density in men.[21,22]