Self-Management of Depression

A Manual for Mental Health and Primary Care Professionals

Albert Yeung, Greg Feldman, and Maurizio Fava





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-AY

I wish to thank my wife, Amy, and our two sons, Benjamin and Samuel, for their support and inspiration.

-GF

I could not do what I do without the extraordinary help and support from my wife Stefania and our son Giovanni.

-MF

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Preface

From the clinician's perspective, a key component of self-management of depression is connecting patients with enduring resources to monitor and manage their symptoms. As such, throughout this book, we provide patient hand-outs containing information to guide their use of self-management, including tips for initiating and sustaining an exercise program and selecting a peer support group, as well as lists of links to Internet resources where patients can find self-assessment tools, information about learning meditation, and web-based cognitive behavioral therapy programs. These handouts may be photocopied and distributed by the purchaser of this book to patients. These hand-outs are also available for download at no cost at http://www.cambridge.org/9780521710084.

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The use of self-management for depression

Major depressive disorder – commonly referred to as "depression" – is a prevalent, debilitating, costly, often chronic, and potentially fatal condition. As many as 17% of people will experience major depressive disorder (MDD) in their lifetime (American Psychiatric Association [APA], 2000). The World Health Organization (2001) predicts that depression will become the second largest cause of disability worldwide by 2020. The economic burden of depression in the United States is estimated to be over \$83 billion per year, including direct medical costs, workplace costs, and suicide-related mortality costs (Greenberg et al., 2003). Despite its high prevalence, many individuals with depression have difficulty accessing adequate care (Kessler et al., 2003; Hirshfeld et al., 1997). In the United States and abroad, there are shortages of trained mental health professionals to address the increasing prevalence of depression. New strategies are needed for delivering efficient and effective treatment for depression. Self-management holds promise as a strategy for identifying, treating, and managing depression.

What is self-management?

Self-management can be defined as the methods, skills, and strategies by which individuals effectively direct their own activities toward the achievement of specific objectives. It usually includes goal-setting, planning, scheduling, task tracking, self-evaluation, self-intervention, and self-development. In health care, self-management typically refers to the training, skill acquisition, and interventions through which patients who suffer from a disease or a chronic condition may take care of themselves and manage their illnesses.

Why is self-management relevant for depression?

The principles of self-management have been successfully implemented in managing many chronic illnesses, including diabetes, congestive heart disease,

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and obesity. Self-management involves a collaborative relationship between the patient and one or more primary care or mental health clinicians. The patient is taught and encouraged to (1) view treatment as a collaborative process, (2) actively self-monitor symptoms, and (3) supplement professionally delivered interventions (antidepressant medication and psychotherapy) by using evidence-based, self-administered interventions; for instance, structured physical exercise programs and interactive computer programs that teach effective coping strategies. Self-management has the potential to empower individuals already receiving treatment and provide them with additional resources. It can also increase access to treatment for individuals in geographically remote areas. By shifting more responsibility for symptom management to the patient, a greater number of patients may access treatment, the efficacy of standard therapies may be enhanced, risk of relapse may potentially be decreased, and clinician time may be reduced, thus freeing up clinicians to treat additional patients. Finally, self-management has the potential to reduce costs associated with untreated or poorly managed depression, including health care expenses, disability, and lost workplace productivity.

Overview of this chapter

As previously mentioned, the principles of self-management have been successfully implemented in managing many chronic illnesses. In this chapter, we will present principles and theoretical models describing approaches to management of chronic illness based upon reviews of programs or treatments found to be successful in managing chronic illness through self-management. We will explain how a collaborative clinician–patient relationship is used to empower patients and how this can be contrasted with traditional approaches to health education. Next, we will preview the approaches to self-management for depression that will be discussed in greater detail in later chapters. From there, we will discuss why patients' own attempts at self-management of depression may be unsuccessful. Finally, we will conclude by discussing six essential components of self-management and discussing research support for collaborative care and self-management in treating several chronic illnesses, including depression.

A note on how to read this book

The overall goal of this book is to provide primary care physicians and nurses, psychiatrists, psychologists, social workers, and other professional caregivers with the knowledge and tools for making their work with patients with depression more efficient and effective by integrating self-management treatment strategies with conventional professionally delivered treatment modalities. Consistent with the collaborative nature of self-management, this book will not present a prescription of a rigid sequence of actions a clinician must take in order to truly use self-management in his/her practice. This book contains no "one-size-fits all" recommendations. Instead, our goal is to present information about approaches used across multiple studies that have worked to increase collaborative care and self-management. Readers are encouraged to think about their own clinical setting and the needs of the patients they serve in deciding how to apply the models and interventions described.

Who needs self-management?

If we use a broad definition of self-management, it can be argued that everyone needs and performs some form of self-management. Every day, we are faced with stress and challenges in life that frequently lead to distress and emotional problems. To maintain a sense of well-being, people usually have their own ways to obtain a sense of emotional well-being. When people suffer from an illness, they may need specific knowledge or skills to respond so that they can recover from the illness, avoid its worsening, or prevent recurrences. There is extensive literature on how environmental factors, emotions, and lifestyles affect health. We make decisions every day on the type of food we eat, how often and how much we eat, how much physical exercise we do, how much time we spend working and resting, the type of activities we do for recreation, the people with whom we interact, and the way in which we interact with them. All of these can be considered as some forms of self-management. We know that what we eat affects our body chemistry. A diet rich in saturated fat could increase our blood cholesterol; elevated cholesterol level is a known risk factor for atherosclerosis, heart disease, and stroke; high caloric intake may lead to becoming overweight and obese; and consuming too many sweets and carbohydrates among people who are predisposed to diabetes may lead to elevated levels of blood glucose.

Patients with chronic medical conditions, in particular, live with and selfmanage their illnesses continuously. Each day, they decide what they eat, whether they will exercise, and in some conditions like diabetes and asthma, the dosages of medications to use. For successful management of their diseases, it is important that patients have an in-depth understanding of their illnesses so that they are able to meticulously monitor their symptoms, adopt healthy lifestyles, and implement treatment plans for their illnesses. Depression can be considered a recurrent and/or chronic disorder in that episodes of depression may recur and/or last for many years. Furthermore, even for patients who recover from an episode, the majority will relapse (APA, 2000). In fact, at least 60% of patients with one episode of depression will experience a second. Seventy percent of those with two episodes experience a third, and 90% of those with three episodes will have a fourth. This book explores what people can do to manage their symptoms of depression through behavioral change, such as lifestyle modification, and how health care providers can encourage and guide patients' use of these self-management strategies.

Self-management of chronic medical conditions

Epidemiology of chronic disease

The population of the United States has a demographic profile that is rapidly aging. As a result, the prevalence of chronic medical conditions associated with aging is increasing at a fast pace. Today, chronic disease is the main reason why people in the United States seek health care, and they consume 70% or more of health care spending (Holman & Lorig, 2000). In most industrialized nations and in many developing countries, chronic diseases are the main causes of disability and death. According to data published by the World Bank, 5 of the 10 leading causes of burdens of diseases (projected years living in disability due to the condition) were chronic diseases, including ischemic heart disease, cerebrovascular disease, HIV/AIDS, unipolar depression, and chronic obstructive pulmonary disease (Lopez et al., 2006).

Goals of treating chronic diseases

The goals in the treatment of chronic disease are very different from those in the treatment of acute illnesses. For acute diseases, the goal of treatment is to eradicate the causes of the disease so that the patients can return to normal. Chronic diseases are irreversible or relapsing conditions that are either persistent or run a wax-and-wane course. They typically interact with environmental factors, recur and remit throughout the lives of the patients, and tend to require continuous and complex management. The goal of chronic diseases treatment is not cure, but to support patients in managing their own diseases so that they can maintain satisfying, pleasurable, and independent lifestyles. There is increasing evidence that self-management educational and supportive interventions are effective in helping patients with chronic diseases change their risky behaviors or become better self-managers, and in improving outcomes across a range of chronic illnesses.

Management of chronic illnesses: is the current US health care system adequate?

With the rising prevalence of chronic illnesses and the increasing attention they have received in recent years, effective treatment has been devised for many of the chronic diseases, such as hypertension, depression, diabetes, and asthma. Yet, less than half of patients with hypertension, depression, diabetes, and asthma are receiving appropriate treatment, according to a recent Institute of Medicine report (Wagner et al., 2001a). This lack of adequate care was partly attributed to the high demands on medical care due to the rapid increase in the prevalence of chronic diseases and partly to the US health care system, which was designed to manage acute illnesses or injuries and not chronic diseases. "The focus of the current health care system is on the immediate problem, its rapid recognition and exclusion of more serious alternative diagnoses, and the initiation of professional treatment. Under such a system, the patient's role was largely passive" (Wagner et al., 2001a).

The current primary care health delivery system provides little support to handle the needed lifestyle changes, such as changes in diet, exercise, and stress management, required by people with chronic medical conditions. It also does not provide patients with assistance in creating and maintaining new meaningful life-roles regarding jobs, family, and friends, nor does it provide guidance in ways to cope with the anger, fear, frustration, and sadness that can be part of the experience of a chronic condition. People with chronic conditions have to successfully overcome all these challenges before they can effectively manage their chronic conditions (Corbin & Strauss, 1988). Wagner (2000) concluded that there was a need to redesign the current health care delivery system in order to provide better care to patients with chronic medical conditions and diseases.

The Chronic Care Model

To improve care for chronic disease, Wagner studied successful quality improvement programs for many chronic diseases, including diabetes, congestive heart failure, asthma, hyperlipidemia, and depression. Wagner (1998) found that what these successful programs had in common was that they used a multifaceted approach and all included one or more of the following provider-oriented components: continuing education to physicians, organizational changes in personnel to facilitate patients' visits and follow-up, information systems changes, and patient-oriented interventions. Based on these observations, Wagner (1998) designed the Chronic Care Model for the management of chronic diseases.

The Chronic Care Model typically includes setting up a clinical information system registry, delivery system design, decision support, self-management support, and community resources and policies. The development of computerized disease registries facilitates systematic tracking of patients with a specific condition, sending reminders to patients regarding their follow-up visits to avoid delayed treatment, monitoring treatment outcomes, and providing feedback to practitioners. The designing of the delivery system involves defining roles in the patient treatment team to delegate responsibilities among the 6

multidisciplinary team members. The goal is to ensure continuity of care by the treatment team and to ensure regular follow-up. Decision support involves the development and implementation of evidence-based guidelines using provider education, reminders, and increased interactions among generalists and specialists.

Of particular relevance to this book, self-management support is considered a key element in the Chronic Care Model. Self-management support emphasizes the patients' central role in managing their illness and provides effective behavior change interventions and ongoing support with peers or professionals. Establishment of community resources and policies involves setting up partnerships with community organizations to develop evidence-based programs and identifying effective programs in the community in which patients may participate. The Chronic Care Model has been found to be successful in over 300 diverse health care systems in the context of quality-improvement efforts for asthma, congestive heart failure, depression, diabetes, prevention of frailty in the elderly, and provision of an extremely helpful organizing framework for these diverse quality improvement efforts (Wagner et al., 2001b; Glasgow et al., 2001).

In the Chronic Care Model, optimal chronic care is achieved when a prepared, proactive practice team interacts with an informed, activated patient. It embraces two major components: collaborative care and self-management education. Collaborative care is established on a new form of patient-physician relationship in which physicians and patients form a partnership relationship. Together, they make health care decisions and implement the treatment plan. In the following sections, we will discuss the principles of self-management with a focus on how the collaborative clinician–patient relationship can promote self-management.

The principles of self-management

In this section, we describe some of the key principles for self-management, including the importance of empowering patients and promoting their self-efficacy through the use of collaborative care and self-management education.

Empowering patients through shared decision making

To live the best quality of life, patients with chronic conditions need to be expert in managing their own conditions and to understand how to avoid intensifying or having relapses of their conditions. Patients are no longer passive recipients of medical care. They need to be partners in the process and to play a key role in making decisions about the choice of treatment, interpreting and managing changes in their conditions, coping with emotional reactions, implementing behavioral changes, and utilizing medical and community resources. Empowering patients facilitates the effective and efficient delivery of health care. It has been found that adopting patient's views about their illnesses was associated with higher satisfaction, better treatment adherence, and greater continuity of care (Holman & Lorig, 2000).

Patients who self-manage their chronic medical conditions are given the responsibility to handle their chronic conditions. This parallels the current trend in medicine to include patients as partners in medical decision making. The 1982 President's Commission for the Study of Ethical Problems in Medicine and Biomedicine and Behavioral Research emphasizes the importance of including patients as partners in medical decision making. The Commission's recommendation can be viewed as a continuation of the movement in the past several decades in the United States to increasingly acknowledge patients' autonomy and to provide full information to patients about their illness so that they can make informed decisions about their treatment. Ignoring a patient's right to know about their medical condition and to take part in deciding on their treatment is considered a denial of their autonomy and a violation of current medical ethics.

As successful implementation of self-management of chronic medical condition requires partnership from the patients, this shifts away from the traditional medical model to the shared decision-making model. The traditional medical model is a more paternalistic model in which the doctor determines the best treatment for the patient. The physician provides the patient with select information in order to obtain his/her agreement with the procedure. The shared decision-making model involves both the doctor and the patient sharing information about treatment options in order to arrive at a consensus regarding the preferred treatment options. As Charles and colleagues (1997) state, "Shared decision making is seen as a mechanism for decreasing the informational and power asymmetry between doctors and patients by increasing patients' information, sense of autonomy and/or control over treatment decisions that affect their well-being." Shared decision making addresses a limitation of the traditional medical model that assumes the doctor is the unquestioned expert and unilateral decision maker. In fact, doctors cannot always make the best decision for their patients because they may know little about the individual priorities of their patients or they assess them incorrectly. The advantages to patients of participating in the decision of what problems to tackle is apparent; while professionals know what is most helpful to manage the disease, patients know their priorities and their limitations and what is feasible to implement given their personal and social environment.

It is believed that by taking into consideration the individual's goals and priorities and his/her view regarding the advantages and disadvantages of different options, shared decision making helps patients better understand and self-manage their disorder (Hamann et al., 2003). In addition, shared

decision making empowers patients by arousing their internal motivation to take responsibility and manage their own conditions. This is more effective than external motivation from professionals for inducing lifestyle changes.

Promoting patients' self-efficacy through self-management education

The central concept in self-management is to enhance self-efficacy, the belief and confidence that patients can make changes in their lives. Self-efficacy is a concept introduced by Bandura as one core aspect of his social cognitive theory (Bandura, 1997). In the context of self-management, self-efficacy is complementary to the idea of empowerment just discussed. While empowerment encourages patients to feel that they are equal with the clinicians in making decisions about their treatment, self-management training promotes patients' self-efficacy by encouraging and guiding them to carry out behaviors to attain their desired goals. Patients with chronic illnesses rely on themselves, with the help of their health providers, family, friends, worksites, and community resources, to adopt healthy lifestyles and behaviors which are beneficial to successful management of their illnesses. According to Bandura, self-efficacy beliefs determine how people feel, think, and motivate themselves to behave. Person with high perceived self-efficacy believe in their capabilities to produce changes to affect their lives. They tend to conduct a more active and self-determined life course. They set up challenging goals for themselves and maintain strong commitment to the goals. When faced with setbacks, they heighten and sustain their efforts and quickly recover their sense of self-efficacy. They attribute setbacks or failures to insufficient effort or deficient knowledge and skills, which are acquirable. They handle challenges with the confidence that challenges can be overcome. People with such efficacious outlooks tend to produce personal accomplishments, have reduced stress, and are less vulnerable to depression.

In contrast, people with low self-efficacy doubt their capabilities and avoid difficult tasks, which they view as personal threats. They tend to have low aspirations and weak commitment to the goals they choose to pursue. When faced with challenges, their confidence is shaken, they dwell on their personal deficiencies, and they start to worry about the obstacles they will encounter and all the possible adverse outcomes. In the end, they tend to succumb to obstacles and to give up their goals. They find it hard to recover their sense of efficacy following failure or setbacks. They easily fall victim to stress and depression.

Based on the theory of self-efficacy, self-management in clinical care is geared to provide the resources and the training in a systematic manner so that people with chronic medical conditions acquire the skills and the confidence to be self-efficacious in the management of their conditions.

The theory of self-efficacy is based on the theme of individual responsibility, implying that people are responsible for their own behavior (Lorig & Holman,

2003). Under such a theme, patients are encouraged and taught the skills needed to take an active part in the management of their chronic medical conditions. They are discouraged from acting as a passive recipient and waiting for health professionals to take away their problems. From a practical point of view, patients with a chronic disease are the ones who perform their day-to-day management and decide whether to engage in a health-promoting activity, such as exercise or diet control. It is impossible, without compromising patients' autonomy as well as privacy, to constantly supervise patients with chronic diseases over the entire extended course of their illnesses.

Studies have shown that patients who are confident in their ability to manage their illnesses are the ones with the best health outcomes (Schwarzer, 1992). Based on the self-efficacy theory, there are four ways that confidence can be increased. One way is for health professionals to collaborate with patients on setting short-term achievable goals so that patients will master new skills. A second way is for patients to meet someone like themselves so that they can learn disease management through modeling. This can be done through patient groups, peer leaders, and, more recently, chat rooms via the Internet. The third way is to assist patients to understand the multiple causes of their symptoms. In doing so, patients may understand that many of their own behaviors may contribute to their illnesses and that the disease can be better controlled through changes in their lifestyles. The fourth way is social persuasion. Praise and encouragement concerning patient's accomplishments by health professionals, friends, and family are important in increasing patients' confidence in what they can do in the control of their illnesses.

Self-management education is designed to enhance self-efficacy so that patients feel confident in managing challenges in their lives. In traditional patient education, health care professionals define the problems and decide what information and skills to teach. Self-management education allows patients to identify their problems that may or may not be related to the disease. It provides techniques to help patients make decisions and to take appropriate actions to respond to changes in their diseases. While traditional health education provides disease-specific information and technical skills related to the disease, self-management education provides problem-solving skills that are relevant to the consequences of the chronic condition in general. The underlying theory behind traditional patient education is that the health professionals know the answers and what is the best for the patient. Once the patient acquires the knowledge, they will be able to implement it and produce better clinical outcomes. Self-management education theorizes that greater patient confidence in his/her capacity to make life-improving changes yields better clinical outcomes (Bodenheimer et al., 2002).

A central feature of self-management education involves patients asking to generate their short-term action plans based on what they want to do. The purpose of action plans is to fuel the patients' internal motivation and to give

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patients confidence in managing their disease. It has been shown that patients who actually make action plans have better outcomes (Bodenheimer et al., 2002).

Traditional patient education in the clinic is usually provided by a health care professional. For self-management education, a health professional, a peer leader, or another patient can be the educator, and it often happens in a group format. The use of lay resources and group settings in self-management education increases the access of self-management education to patients with chronic diseases in an economical and efficient way.

Self-management of depression

The concept of clinical depression

Clinicians who treat patients with depression need to know how severe their depression is and whether intervention is warranted. It begs the fundamental question: "When does depression become a clinical condition and a disease?" "In the human population, is there a natural or continuous distribution of depressive symptoms and we simply consider people clinically depressed if they fall on the more severe side of the continuum, or do we consider clinical depression a distinct disease entity that involves a unique pathological mechanism?"

Instead of directly answering these questions, the American Psychiatric Association (2000) adopts an atheoretical approach in the Diagnostic and Statistical Manual Fourth Edition Text Revision (DSM-IV-TR) and defines depressive disorders based on the presence of a cluster of symptoms, duration of symptoms, and whether they have caused significant distress or functional impairment to the person suffering from the symptoms. Using major depressive disorder (MDD) as the example, its diagnosis involves the presence of five of more of the depressive symptoms, one of which needs to be depressed mood or loss of interest or pleasure in the activities that used to be enjoyable. Other symptoms in the DSM-IV-TR diagnostic criteria for MDD include changes in sleep or eating patterns, agitation or retardation, fatigue, inability to concentrate, indecisiveness, feelings of worthlessness or excessive guilt, and suicidal thoughts. The symptoms would need to last for 2 weeks or more, and must have caused either significant subject distress or impairment in social and occupational functioning. In addition to these symptoms described in the DSM-IV-TR diagnostic criteria, depressed patients may also demonstrate symptoms associated with depression, including anxiety, irritability, preoccupation with physical heath or complaints of pain, brooding, obsessive rumination, and pessimism (APA, 2000).

The DSM-IV-TR criteria of MDD, informed by research and established by expert consensus meetings, offers an agreed-upon definition which has