Chapter 5
Self-Management Techniques in IBD

Laurie Keefer and Sunanda Kane

Introduction

Lifelong management of inflammatory bowel diseases (IBDs) encompasses a range of medical and surgical approaches designed to maintain disease remission and optimize quality of life, including acute symptom management (flares), flare prevention/maintenance of remission, colon cancer surveillance, monitoring of comorbidity, and the consequences of complex medication regimens [1, 2]. The irony of this modestly effective approach to IBD is that, irrespective of the strength of an IBD care team, an individual will still likely spend less than 3 h per year obtaining care or in communication with their provider(s) [3] and the rest of the time managing uncomfortable and embarrassing symptoms, disability and functional impairment, complicated medication regimens, demanding lifestyle changes, and coordination of medical care and health insurance on his/her own [4, 5]. In other words, *everyone with IBD self-manages, however well or poorly that management might be*.

In a changing health-care climate in which national priorities of reducing costs and improving quality focus largely on prevention of health episodes in which health-care costs are highest (reducing readmissions), incentivizing collaborative care, patient education, and transparency (meaningful use) and emphasizing patient and provider responsibility for long-term outcomes [6], effective patient self-management is more important than ever.

In this chapter, we (1) define self-management and discuss the unique features of IBD which make self-management particularly challenging, (2) describe the role of self-management support, including health-technology-enabled support, on health

S. Kane (✉)
Division of Gastroenterology and Hepatology, Mayo Clinic Rochester,
Rochester, MN 55905, USA
e-mail: kane.sunanda@mayo.edu

L. Keefer
Department of Gastroenterology and Hepatology, Northwestern University
Feinberg School of Medicine, Chicago, IL, USA

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outcomes in IBD, and (3) discuss the importance of social-cognitive theory in the development and implementation of self-management support for IBD, including the types of techniques and constructs which fit within this model.

Defining Self-Management

Self-management is a behavior that cannot be avoided—rather, it is one which operates on a continuum of healthy to maladaptive. The goal of self-management is to engage in a set of behaviors that allows one to maintain emotional and physical wellness in the setting of chronic disease over time. "Good Self-Managers" have been characterized by Dr. Kate Lorig, a pioneer in this area as "individuals with chronic diseases who make informed choices, adapt new perspectives and generic skills that can be applied to new problems as they arise, practice new health behaviors, and maintain or regain emotional stability" [7].

Self-management of chronic illness is characterized according to the degree to which someone can effectively engage in three interrelated tasks: (1) medical management (medication adherence, decision-making, disease knowledge, patient–provider relationship or communication), (2) preserving or creating meaningful life roles in context of the limitations a disease presents, and (3) acknowledging and managing the emotional or psychological impact of chronic disease. Within each of these self-management tasks, there are five core skills that determine one's success—these include (a) problem-solving, (b) decision-making, (c) resource utilization, (d) forming a collaborative relationship with a health-care provider, and (e) taking action/implementing change (Fig. 5.1; [7]).

The Self-Management Challenge in IBD

Not surprisingly, the majority of self-management interventions in IBD are based on the task of medical management and the skills of problem-solving, resource utilization, and decision-making. However, self-management is more complex than this. Indeed, the risk of flare as well as the efficacy and dosing of medications required to induce and sustain remission is directly influenced by self-management behaviors, including adhering to medication [4, 8–20], managing stress and psychological well-being [21–30], coping [29, 31, 32], managing the patient–physician relationship [10, 15, 33–36], smoking [37, 38], and maintaining relevant disease knowledge [35, 39–41]. There are several reasons why self-management of IBD is such a challenge:

1. IBD differs from many chronic diseases in that, even when patients are optimized medically and "doing everything right," disease flares can still occur.
2. Because the majority of patients are diagnosed between the ages of 15 and 35, they cycle for decades with periods of acute symptom management (disease

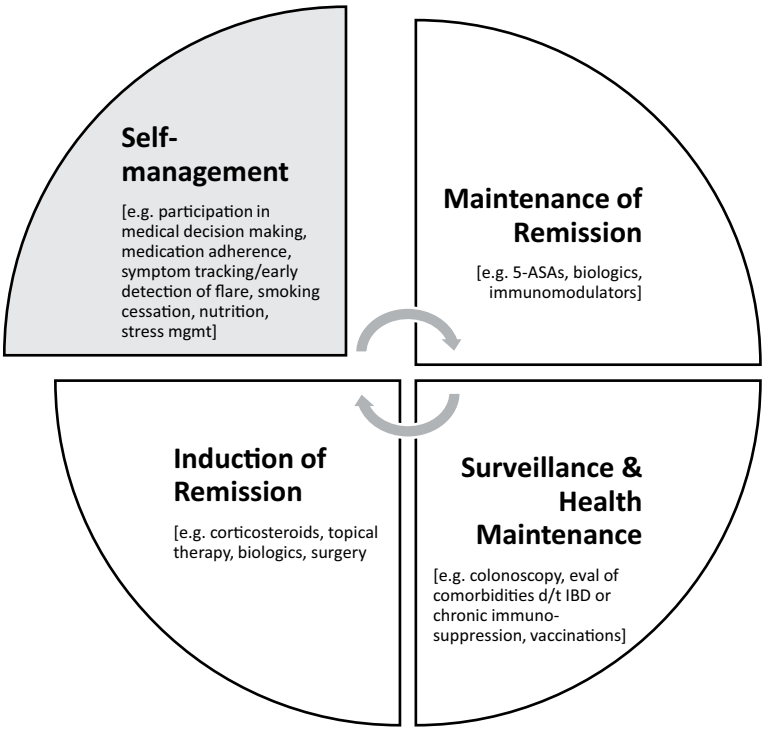

Fig. 5.1 Components of effective inflammatory bowel disease *(IBD)* management

flare), flare prevention (maintenance medication), cancer/risk surveillance, and lifestyle modification (Fig. 5.2).

3. Disease parameters, psychological well-being, and quality of life are directly affected by where a patient fits in terms of flare versus remission [42], their current treatment regimen (e.g., corticosteroid use) [43], and access to quality care [44].
4. In addition to shifts in disease course and cycle, as patients age with the disease and meet developmental milestones, there are critical shifts in social support (e.g., young adults moving out of the home with caregivers), financial resources, stressors, comorbidity, and self-management skills are readily impacted [45].
5. IBD symptoms themselves (fatigue, urgent diarrhea) affect one's ability to engage in complex disease management behaviors such as coordinating care across providers, especially if a patient is receiving treatment across different hospitals and emergency departments, making decisions based on evidence and nonphysician recommendations (e.g., online resources), deciphering test results, storing and organizing medications over multiple settings, and implementing behavior change in multiple contexts [46].

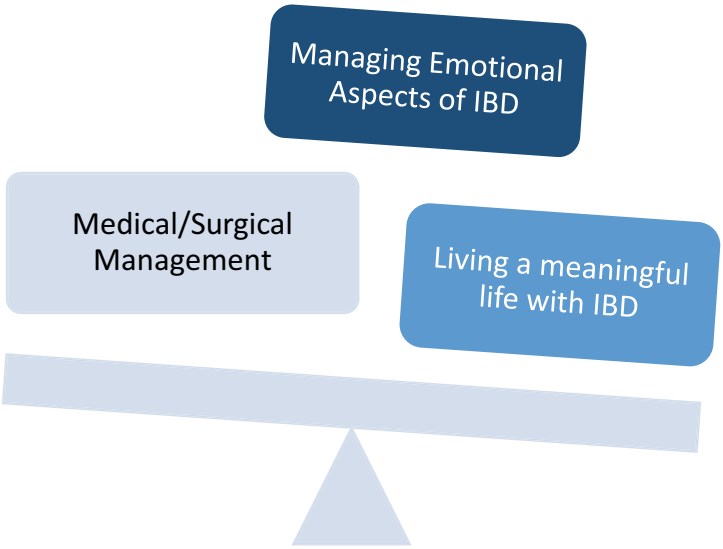

Fig. 5.2 Primary tasks of effective self-management

6. Self-management skills are further complicated by sociocultural barriers, including access to care, health literacy, social support, language, and access to online information [46].

Unfortunately, not all patients are successful in all aspects of self-management. Indeed, IBD patients who have difficulty adapting to disease-related demands report more bowel and systemic symptoms, more pain, less engagement in activities, higher perceived stress, an emotional representation of illness, and higher health-care use [41].

Self-Management Support

Strong self-management skills and high patient engagement lead to healthy outcomes in IBD [13, 47]. Self-management support or the use of behavioral tools and techniques to foster skills building and self-efficacy, when properly administered, can dramatically improve health outcomes [48]. Self-management programs that address a patient's chronic disease in context can ultimately improve the efficacy of treatment through improved disease knowledge, improved communication, increased adherence, better self-monitoring, less health-harming behaviors (smoking), and better self-care [49]. As such, when treatments are more effective, outcomes improve quality of life, decreasing disability, reducing need for surgery shortening flare course, and decreasing health-care costs [50]. Figure 5.3 represents a model linking self-management support to health outcomes.

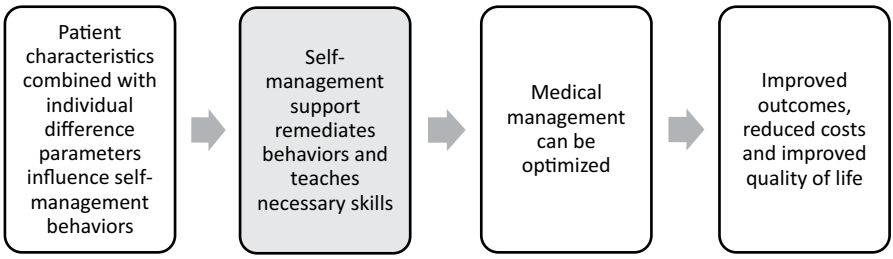

Fig. 5.3 Relationship between self-management support and outcomes

Effective self-management is based on the accomplishment of tasks and building of skills over the entire course of a disease. Again, the core skills that determine one's self-management success include (a) problem-solving, (b) decision-making, (c) resource utilization, (d) forming a collaborative relationship with a health-care provider, and (e) taking action/implementing change [7]. For most individuals, developing and refining these skills requires varying degrees of self-management support over time. Indeed, optimizing self-management support has been an increasing focus of governmental and health-care organizations, described in the famous "Crossing the Quality Chasm" report from the Institute of Medicine [51], and as implemented in patient-centered medical homes and mandated in the Patient Accountability and Affordability HealthCare Act (H.R. 3590, 2009).

Self-management support programs are typically problem based, meaning they identify and promote the development of skills that solve a critical aspect of disease management. Tools or programs which support skills such as improving medication adherence, increasing disease knowledge, implementing decision-support tools, or optimizing communication between patients and providers are all problem-focused ways in which IBD self-management can be readily supported. For a review of self-management/education programs in IBD, see C. Barlow et al. [52].

Self-Management Support Through Psychotherapy

Most self-management support programs in IBD and other diseases focus primarily on the core task of medical management, with less emphasis on preserving or creating a meaningful life or managing the psychological impact of the disease. The exception to this is the use of psychotherapy in patients with IBD. A review of 18 behavioral trials for IBD demonstrated that brief, problem-focused psychotherapies such as cognitive-behavior therapy may actually show promise with respect to reducing pain, fatigue, relapse rate and, hospitalization and improving medication adherence [53]. This notion is supported by the work of Knowles and colleagues, who point out that if psychotherapies are grouped according to their theoretical approach, skills-based interventions for IBD tend to have slightly better impact [54]. More traditional psychological interventions, a.k.a. "talk therapy" which have the

potential to affect self-management tasks 2 (meaningful life) and 3 (psychological impact) in addition to medical management, have also been employed in IBD with mixed results—unfortunately, many of these programs did not address disease-specific concerns [50–57] or limited their scope to IBD patients with frank depression or anxiety [54, 57, 58].

Self-Management Support Through Health Technology

Chronic disease research suggests that the degree to which patients can fully engage in their health care is determined by the extent to which they can access culturally, linguistically appropriate information directly relevant to their specific disease state or concern at the exact time they are looking for it [55–62].

Mobile and web-enabled self-management solutions can drastically reduce the environmental barriers for a wider overall reach, heighten the cost-saving economic impact of chronic illness self-management programs, and address accessibility factors associated with disease outcomes, including the timeliness and pertinence of both support and disease information. By providing these, tailored to the individual, mobile self-management solutions are limited in access only by one's ability to connect to the Internet [63].

Health information technology in the form of online support groups, social networks, and education platforms are adopted and used by a modest subset of IBD patients demonstrating patient interest and potential or perceived benefit [47]. As we discussed previously, the self-management demands of IBD are long term and constantly changing, which makes it difficult to keep content and tools relevant. Table 5.1 lists examples of health information technology (IT) self-management tools.

Social-Cognitive Theory and Self-Management Support for IBD

While traditional self-management programs targeting a single problem can be quite effective, self-management support initiatives may be better suited to approaches which integrate the complex interactions between the thoughts, feelings, and behaviors that accompany IBD (patient modifiers) and the physical and environmental demands the disease presents (disease modifiers). Social-cognitive theory can be readily leveraged for the development of self-management support tools for IBD. In this model, knowledge about the importance of a skill is a necessary but not sufficient way to promote health behavior change. Rather, individual perception (perceived risk, trust in medical provider), motivation, skills, and the environment are all important contributors to a patient's ability to adapt to ever-changing disease-related demands (Fig. 5.4; [69]).

Table 5.1 Common categories of problem-based online disease self-management tools

Medical advice/disease knowledge
Online conversations cover a wide spectrum of health-care and lifestyle topics and serve as a place where personal information is freely shared and important decisions about treatment options are openly discussed. While physicians who provide answers to questions posed by patients online may have their best interests in mind, the unstructured and uncontrollable nature of online discussion may result in incomplete portrayals of patient and disease profiles and render patients susceptible to inappropriate, potentially detrimental, and/or suboptimal recommendations. Foundation-sponsored patient education websites (e.g., www.ibdetermined.org) target a relatively small subset of highly motivated, high health-literate patients [64] who do not require the tailored, specialized structure and motivational components which consider individual lifestyle, disease characteristics, and personal preferences to foster effective disease self-management [47]
Social-support tools
Online peer support networks provide reported social and emotional benefit to patients [65, 66] and potentially provide insight into beneficial disease self-management practices, but the uncontrolled nature of peer-to-peer interaction and unknown agendas of website users also puts patients at risk for exposure to inaccurate information and could undermine the collaborative decision-making process between doctor and patient
Symptom-tracking tools
There are now over 5000 medical applications available to download from various web and mobile application stores, and the number continues to rise as health-care digitization continues [67]. One IBD example is from the Crohn's and Colitis Foundation of America (CCFA), who released the web- and mobile-enabled app "GI Buddy" in January 2013, which features a set of tools focused on different tracking activities. While the barriers to access are low in this format, motivation to continually engage with these applications is lacking
Decision-support tools
Decision-support tools are developed in an effort to make complex medical information (e.g., on biologics and dual therapies) easier to understand, allowing patients to make informed medical decisions in line with their personal preferences for treatment [68]

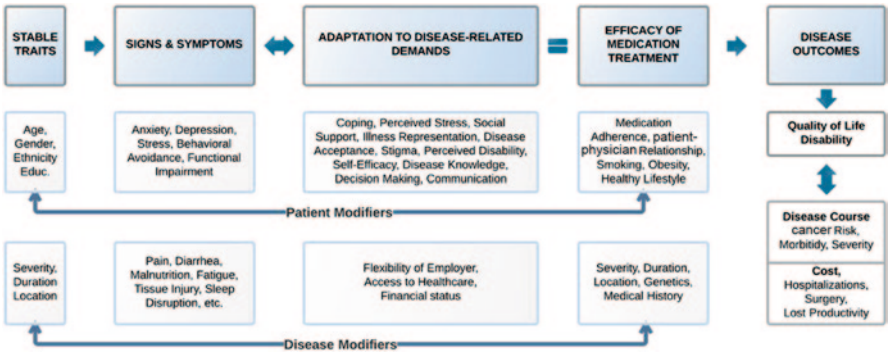

Fig. 5.4 Social cognitive model of inflammatory bowel disease *(IBD)*. Interventions that target the dynamic interactions between these variables have the potential to improve the efficacy of treatment and thereby impact disease outcomes

Social-Cognitive Techniques

Social-cognitive theory carries with it a set of behavior change techniques, which are applicable to chronic disease self-management. These techniques can be classically thought of as either respondent or operant in nature.

Respondent techniques are based on principles of classical conditioning and target the physiological responses (e.g., arousal, vasovagal symptoms, and immune function) to aversive stimuli (e.g., stress, injection phobias). Progressive muscle relaxation, guided imagery, breathing retraining, and hypnotherapy are all examples of respondent-based interventions. These are often used to promote coping, emotional well-being, and reduced physiological arousal associated with disease-specific tasks (e.g., anxiety around ostomy, needle-injection phobias, difficulty swallowing pills). Techniques such as mindfulness-based stress reduction and relaxation-based therapies can be particularly helpful when patients have IBD with chronic abdominal pain not linked to intestinal inflammation or if they have concurrent irritable bowel syndrome, as these techniques simultaneously target the brain-gut axis, pain catastrophizing, and other key aspects of functional gastrointestinal (GI) motility and pain disorders [70–72]. Similarly, hypnotherapy for ulcerative colitis seems to have a positive effect on the immune-inflammatory response [73] and may prolong maintenance of remission [74, 75].

Operant techniques are based on principles of instrumental conditioning [76]. These techniques work to diminish the cognitive-affective and environmental contingencies that maintain negative health behaviors and to promote and reinforce acquisition and implementation of healthy behaviors. Operant-based interventions foster change through the direct manipulation of personal consequences. For example, if a behavior change (improved adherence) leads to a favorable outcome (maintaining remission), an individual will be more likely to engage in that behavior

going forward (positive reinforcement). If a behavior change (improved adherence) is associated with the removal/reduction of an aversive stimulus (ability to taper off of corticosteroids), an individual will be less likely to forget to take his/her medicine (negative reinforcement). If a behavior (smoking) leads to an unfavorable outcome (flare), a person will be less motivated to engage in that behavior (punishment).

For example, in the "Project Management for Crohn's Disease" study [77], patients were asked to identify a single health behavior which undermined the efficacy of his/her treatment. Skills training was provided individually over six weekly sessions to 16 adults with quiescent Crohn's disease (CD) and mirrored project management methodology, including viewing CD as a project that could be managed, allocating personal resources to disease management (e.g., assertiveness around saying no, choosing which aspects of their life they valued most, etc.), self-monitoring of progress, removing barriers, consulting with experts (nutritionist, personal trainer, smoking cessation support group), and risk management. Another 12 adults with quiescent CD underwent treatment as usual. While the sample size was small and results were preliminary, the project management outperformed usual care in each target domain—Inflammatory Bowel Disease Questionnaire (IBDQ) total score, IBDQ bowel and systemic subscales, IBD self-efficacy, and perceived stress.

In another operant learning-based self-management support program focused on fatigue in IBD [78], 29 patients with quiescent CD and high fatigue scores were randomized to solution-focused therapy (SFT), problem-solving therapy positive control group, or treatment as usual. SFT was administered in the form of five sessions over 12 weeks and offered a wide range of self-management skills focused on helping a patient make a behavior change around fatigue. SFT improved fatigue ratings in more than 85 % of patients and was superior to both control groups.

Telemanagement approaches are particularly conducive to operant techniques as reinforcement and punishment feedback can be readily translated into online formats (acquiring or losing points/tokens/badges, being able to move to a new level) [79–81].

Disease Self-Efficacy

The final characteristic of effective self-management programs, also a main component of social-cognitive theory, is that they build self-efficacy. Self-management support programs promoting self-efficacy have been linked to healthy disease outcomes in cancer [82], multiple sclerosis [83], heart disease [84], diabetes [85], and to long-lasting health behavior change [86].

Self-efficacy occurs when an individual's perception of his or her ability to adopt new health behaviors improves as he or she encounters new experiences that affect his or her thoughts and beliefs [87]. Self-efficacy is determined by the degree of success or mastery an individual believes he or she has with a specific behavior change. However, self-efficacy is also strongly influenced by reinforcement from key people (e.g., spouse, physician, nurse, psychologist) and the ability to self-

regulate any physical or emotional discomfort associated with a behavior change. Self-efficacy can be acquired in IBD and may be one of the most important predictors of successful adaptation to disease-related demands [41, 88].

There are three ways to foster self-efficacy: (1) personal experience, (2) vicarious experience (peer support, testimonials), and (3) in the presence of supportive environmental contingencies (clear reinforcers). Again, telemanagement approaches can readily garner support for all three learning techniques (Table 5.2).

In a large, randomized controlled trial of self-management-based training, 700 IBD patients were followed over 1 year after receiving either self-management training or nothing and at the end of 1 year; self-managing patients were found to have higher confidence in their ability to cope with their condition, which predicted improved quality of life, health service resource use, and patient satisfaction [89]. Similar results have been found in other studies [90] as well as with adolescents, particularly in the context of transition care [91, 92].

Conclusion

In this chapter, we discussed the unique self-management skills of IBD patients in the context of social-cognitive theory. The bottom line is that when self-management support focuses on disease-specific problems (fatigue, adherence), it can be very effective. However, as described from a social-cognitive framework, the challenges in promoting optimal self-management in IBD are quite complex and poorly understood.

Limitations in Our Understanding

There are a few obstacles to widespread dissemination of self-management support tools for IBD. First, heterogeneity across disease status leads to serious gaps in the promotion and implementation of patient self-management support tools, with individual patient characteristics interacting with disease characteristics to add complexity to the medical decision-making process. Because patients differ by diagnosis (Crohn's, ulcerative colitis, indeterminate colitis, etc.), anatomical location (small bowel, colon, both small bowel and colon, upper gastrointestinal tract, left-sided colon, pancolitis, etc.), disease behavior (inflammatory, fibrostenotic, fistulizing), severity (mild, moderate, severe), individual response to treatments, presence and type of extraintestinal manifestations, surgical history, and genetic contribution of IBD [93, 94], medical decision-making support tools must be quite sophisticated and customized.

Second, viewing IBD self-management behaviors as a singular construct may result in inaccurate assessment of the patient's self-management need or problem. For example, a patient who has an injection phobia and therefore misses doses of their

Table 5.2 Social-cognitive theory applied to inflammatory bowel disease (IBD) self-management need

A 33-year-old, married female patient with peri-anal CD for the past 5 years, is told by her gastroenterologist (GE) that her disease has progressed to the point where her temporary ostomy should be converted to a permanent one. Social-cognitive theory predicts that the patient would be most likely to follow recommendations and be successful if she:
Holds positive outcome expectations: The patient trusts her gastroenterologist's recommendation (or has received a second opinion consistent with her doctor's) for surgical treatment and is 80% confident she will feel better once this is done
Learns about others' experiences: One of the nurses in her surgeon's office puts her in contact with another young, married woman who has also recently had a permanent ostomy for similar reasons and is doing great
Acquires the skills necessary: The patient signs up for an ostomy class run by the surgery nurses to better understand how to order the supplies she needs, how to maintain the wound, purchase underwear, swimsuits, and lingerie that hide the bag, etc.
Immediately experiences positive effects: Within 2 weeks postsurgically, the patient feels more energy than she has in years and has stopped experiencing foul-smelling drainage from her rectum. She thinks she may be ready for sexual intercourse again
Receives positive reinforcement over time: One year postsurgically, the patient applies for and receives a promotion at work. The patient reports that she was able to do this because of the confidence she has gained since having the permanent ostomy. The patient gets pregnant while her disease is in remission and has a healthy baby boy
Has high self-efficacy: Based on her experiences to date, the patient is now confident she can successfully perform the skills necessary to manage the ostomy and anything that might come her way IBD-wise in the future

CD Crohn's disease

biologic may be highly adherent to his/her oral medications. Providing a patient with a text reminder to take medication may seem on the surface to help with an adherence to a biologic but may be largely ineffective. *Context is critical to the application of self-management tools and such tools should not be applied in isolation*.

Disease heterogeneity and chronicity limits the utility of "kitchen-sink" self-management programs; it is difficult enough to engage patients in self-management programs given the profound lifestyle and behavior changes often indicated, but nearly impossible without any clear, personally relevant, disease-altering incentives. The challenges of managing IBD change over time and require new or modified skills as the disease progresses, meaning that onetime exposure to self-management training is inadequate and possibly even detrimental if a behavior that was at one time adaptive, later interferes with optimal management. Future research in this area is needed to meet the quality recommendations for chronic disease care.

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