

Review Article

PRACTICAL POSSIBILITIES TO EMPOWER PATIENTS IN MANAGEMENT OF INFLAMMATORY BOWEL DISEASE

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ABSTRACT

Inflammatory bowel disease (IBD) can be a very embarrassing disease and has a serious impact on the day-to-day lives of the patients and their families. The practical implication of the need to access the toilets frequently and manage situations and people in day-to-day life is a prime concern for most of the patients. If right resources and support are provided to these patients, it can make their day-to-day living easier. The article highlights the concerns of the IBD patients wherein they face hurdles in their personal, professional and social life. It guides on self-management of the disease and encourages them to stay optimistic in fighting with the physical and emotional effects of the disease. In addition, the article captures a few interesting initiatives taken up the patient associations and pharma companies to create awareness and support to the patients. Patient education and support in the form of services/initiatives from healthcare stakeholders can empower the patients to take control of their lives despite the debilitation caused by the disease. With the prevalence of the disease increasing, it is extremely pivotal to create awareness about the disease among the general public as well to empathize the situations of the IBD patients.

Keywords: Inflammatory bowel disease (IBD), Patient care, Awareness, Services, Patient support program and living with IBD

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INTRODUCTION

Inflammatory bowel disease (IBD) involves chronic inflammation of the gastrointestinal tract. The underlying etiology of IBD is not completely understood. However, research indicates that genetic predisposition, environmental factors and malfunction of the immune response to own host cells (autoimmune response) in combination are responsible for the development of IBD [1]. Ulcerative Colitis (UC) and Crohn's Disease (CD) are the principle types of Inflammatory Bowel Disease.

UC is characterized by inflammation and ulceration of the mucosal and submucosal layers of the rectum and the large intestine. Unlike UC, Crohn's Disease can affect the entire gastrointestinal tract and involve all layers of the intestinal wall [2]. The common symptoms of IBD include persistent diarrhea, rectal bleeding, abdominal pain, fever and tiredness. If symptoms are left untreated, it may lead to complications like bowel obstruction, abscesses, fistulas, malnutrition, and colon cancer [2].

UC and CD are unpredictable diseases in which patients can either achieve disease remission after a single attack or require frequent hospitalizations and surgery [3]. There is no cure for IBD and therefore management of the disease is of prime importance [1].

Living with IBD

Most patients with IBD continue to perform the daily functions of their life. However, living with IBD is quite a challenge in patients whose symptoms flare-up. IBD can also be an embarrassing disease for the patients as it can impact their day-to-day life, mainly due to the associated psychological (emotional) symptoms [4]. The practical implication of the need to access the toilets frequently and manage situations and people in day-to-day life is a prime concern for most of the patients [5].

IBD can affect the personal and social life, and on the ability to travel, study and work [6-8]. On a personal front, the IBD patients are concerned about relationships, getting married, having children and raising a family [4]. The impact on social life may result in distress in a relationship with the friends, family members, colleagues and employer [9]. IBD can also affect participation in activities like exercise and sports.

Management of IBD

Irritable bowel syndrome is a chronic condition and there is no known medical or surgical cure. Therefore the treatment should focus on helping patients cope with the symptoms of IBS, rather than addressing the cause. IBS patients with mild symptoms respond readily to education, reassurance, and dietary interventions. Drug therapy should be reserved for patients with moderate to severe symptoms that do not respond to conservative measures.

The treatment goal should focus to improve the quality of life the patients, alleviate the symptoms, reduce the intestinal inflammation, maintain corticosteroid-free remissions, prevent hospitalizations, surgery and maintain healthy nutritional status. These agents should be viewed as being adjuvant rather than curative [10].

The conventional step-up therapy has been partly replaced during the last decade by potent drugs and top-down therapies. Step-up therapy is a method in which the intensity of the treatment increases with the severity of the disease. The top-down approach is a strategy in which the physicians start with intensive treatment (like biologics) to prevent future complications. The treatment of the disease involves the use of anti-inflammatory drugs that can significantly reduce the symptoms of the disease and help maintain its remission [11]. Medications used to treat the symptoms of IBD include anti-inflammatory drugs (5-aminosalicylic acid), and immunomodulators (such as azathioprine, mercaptopurine, methotrexate, infliximab, adalimumab, certolizumab, and natalizumab). IBD management often requires long-term treatment based on a combination of drugs to control the disease. Given the wide spectrum of symptoms, no single agent is expected to provide relief in most of the patients. Therapy targeted at the specific dominant symptom (pain, constipation, or diarrhea) may also be beneficial [11, 12].

The conventional therapies and biologics aim to control the inflammation and exacerbated immune response. Biologics like anti-TNF antibodies (such as infliximab, adalimumab, certolizumab pegol, and golimumab), anti-IL12/23 IgG1 kappa human monoclonal antibody (ustekinumab) and alpha-4 integrin inhibitor (natalizumab) have shown great efficacy, especially in those patients refractory to conventional treatments. However, these biologics are expensive and have undesirable side-effects (immunosuppression, hypersensitivity, autoimmunity, etc.) [13, 14]. It is extremely pivotal in the management of IBD to provide information about the disease

to the individual patients. Active participation of the patients can be helpful for the physicians make informed decisions. Clinicians should be aware of possible drug interactions and side effects. Often, patients will require surgery, and close collaboration is required between surgeons and physicians to optimize the patient’s therapy. In addition, adherence to lifestyle factors like avoiding smoking, maintaining a prudent diet regimen, and minimal exercise can be crucial during the course of the disease [15].

In recent years, research is focused in the area of cellular therapy to identify new targets for IBD patients. The characteristic of stem cells to self-renew and regenerate tissues, together with their immune modulator potential, has been investigated as an alternative therapy for IBD. Stem cell therapy, which includes autologous hematopoietic stem cell transplantation (HSCT) and mesenchymal stem cells can be used to treat severe CD for non-responders to medical treatment in whom surgery is unable to solve the disease [11].

Alternative therapy

Apart from the conventional pharmacological therapies, alternative forms of medicines in IBD also have gained traction in recent years. These include traditional practices such as acupuncture, traditional Chinese medicine, Ayurveda, homeopathy and herbal medicine, as well as more modern complementary practices like aromatherapy, biofield therapies, massage and reflexology. The use of herbal therapies and probiotics is widespread and commonly increasing in IBD patients. The mind-body interventions like meditations, hypnotherapy, exercise and creative therapies like art, music can help in relieving psychological symptoms associated with the disease [16, 17].

Interesting initiatives to support IBD patients and improve quality of life

Considering the general lack of awareness among the general public about the disease, it is difficult to understand the plight of the life of

the patients. The reactions and comments from the people around the IBD patients can be difficult to manage and may even be hurtful. This kind of instances may create stress, anxiety, and lack of confidence among the patients. Hence, the support and guidance to manage the disease have effectively been of utmost importance to bring harmony in the lives of the IBD patients.

In addition, to supporting in the form of services/initiatives, patient education can help to empower patients to take control of their lives despite the debilitation caused by the disease.

This article highlights certain interesting initiatives taken up the patient associations and pharma companies to create awareness and support the patients which are as follows:

IBD patient passport

The prognosis of IBD demands the track of medicines (steroids, biological and immune modulators), colonoscopies, past surgeries, bone mineral densitometry and other relevant information. Also, IBD patients face a unique set of issues during the patient journey, which should be addressed in a customized manner. In such context, the need for summary or outline about the disease will benefit patients and their health care providers to extend great.

The IBD passport serves as a guide to the patient and physicians to track what tests or medications are required and at what time or stage of the IBD. However, the IBD passport is not meant to replace the standard medical record which has each and every detail of the patient. It is just a tool to empowering patients to comprehend better and manage their disease [18]. Various IBD patient passports were launched by the pharma companies, or the reputed patient organizations have been successful in supporting patients and physicians (table 1).

Table 1: IBD patient passport [19, 20]

Patient passport	Company/Organization	Salient features
My Crohn’s Passport	Developed by AbbVie and supported by CDHF, CCC and CAG*	a) The passport (booklet) helps the patients to record details of their illness, investigations, treatments and contacts. b) Patients can record the details of vaccination to prevent risk of infections due to anti-TNF therapy. c) Serves as a guide to the specialist to make better decisions about appropriate therapy.
My Health Passport for IBD	The Hospital for Sick Children, Canada	a) It is a customized, wallet-size card that gives instant access to individual’s medical information. b) Available freely online wherein patients can submit their details and take a print copy for future use. c) Serves as a portable medical record to be used for medical visits and in case of emergency.

*CDHF-Canadian Digestive Health Foundation; CCC-Crohn's and Colitis Canada and CAG-Canadian Association of Gastroenterology.

Scholarship programs

Crohn’s disease and Ulcerative colitis are most frequently diagnosed between 15-30 y of age [21]. The disease affects the young people in the majority of cases and thus has an impeding effect on their education. As there is no cure, the young people living with IBD will need strategies to counter the illness despite their diagnosis. In support of the challenges faced by the bright academic students,

scholarship programs allow them to pursue their educational or professional dreams and excel in life. Realizing the need to pitch these students as role model to inspire other students living with IBD, a patient organization with support from pharma companies have initiated programs to support the education of the IBD patients. An IBD Scholarship program initiated by AbbVie in association with the Crohn’s and Colitis Canada has helped young patients in their educational endeavors (table 2).

Table 2: AbbVie’s IBD scholarship program [21, 22]

Program	Company/Organization	Salient features
AbbVie’s IBD Scholarship Program	AbbVie in association with Crohn’s and Colitis Canada	a) AbbVie in association with Crohn’s and Colitis Canada provides education grants to Canadian students living with UC or CD who are entering into or currently attending a post-secondary educational institution in Canada. b) Each year applications are invited and winners are selected by the independent selection committee of leading gastroenterologists, community partners and patient representatives from across Canada.

IBD mobile apps

IBD patients can avail all the features options using the IBD apps via smartphones or laptops. The mobile apps can optimize access to

care and create awareness about the services provided by the patient advocacy groups or the pharmaceutical companies [23]. Customized mobile apps are freely available for IBD to cater to the needs of the patients and the HCP’s treating them to synergize and

optimize the compliance for the disease management (table 3). The features like, medication records, medication reminders, nutrition tips, information guides and toilet finder option will aid the patients to manage IBD in their day-to-day life [24-29].

IBD art gallery

On 20th February, 2014, AbbVie had launched an art gallery named as 'Perspectives–Art, Inflammation and Me'. This initiative was designed to depict the unknown or the unmet needs/ignored burdens associated with the immune-mediated inflammatory diseases through artistic expressions in the form of sculptures, paintings, photographs, and installations. Notably, more than 100 unique artistic expressions were showcased in at the 9th Congress of the European Crohn's and Colitis Organization (ECCO) in Copenhagen, Denmark. More than 200 artists from more than 40 countries participated in creating awareness of the disease and disseminate the patient stories from an emotional viewpoint through art [30, 31].

A few of the creative artworks presented in the program are described as follows [30, 31]

- 'Tic Tac Toe' by Barbara Miller is a stitched artwork which represents that living with CD is like a game of tic tac toe wherein the player wins, losses and draws. Thoughtfully, the words like endurance, hope, pain and courage, etc., speaks about the emotions experienced during the patient journey.
- 'Captive?' by John Minihan is a photograph taken at a historic jail in Ireland, which is analogous to enmeshment as felt by the patient suffering from UC
- 'Coexistencia' by Guillermo Ros Lluch is a sculpture made of iron, which represents the protective covering patients constructs to face the impact of the disease. However, the intestinal area is made up of marble which is compact and hard to symbolize the disease itself.

Table 3: Mobile apps and their features [24-29]

Mobile app	Country	Company/Organization	Salient features
myIBD App [24, 25]	Canada	Developed by the SickKids Hospital with support from AbbVie	a) An empowering tool for younger patients to track their symptoms and anticipate potential flare-ups b) Helps to record symptoms, stool consistency, pain, frequency of washroom visits on their mobile c) App compiles the information in visual graphs to provide insights to the physicians d) Provides educational videos, dietary tips and medication records
GI Buddy [26]	US	Developed by CCFA* and website is supported by an educational grant from AbbVie and Janssen	a) The app provides various features for recording symptoms, food intake, IBD treatment track and also overall well-being. b) The detail entered by the patients is delivered in the form of dashboards or trend graphs with valuable insights. Thus, the app helps to provide data to the healthcare team on how IBD affects the quality of life of the patient and the measures to be taken to manage IBD effectively. CED App was developed with views from physicians and IBD patients to suit each user's individual needs with the following features: a) Documentation: Typical symptoms and other effects of the disease can be documented by the patients. b) Evaluation: The data documented is analyzed and reported in the form of charts or tables which can be sent via email to the specialist. c) Patient Records: Archives patient reports, discharge letters and other documents. d) Drugs and Medicals: List of medications in use, medication reminders, contact details of the specialists are maintained. e) Calendar: Doctor's appointments and missed days and relapses are stored.
CED App [27]	Germany	Developed by AbbVie	The ECCO IBD Mobile App offers up-to-date data and publications on IBD as well as information on ECCO Congress. Also provides information about ECCO guidelines, news, activities, workshops and membership details.
ECCO IBD Mobile App [28]	EU	Developed by ECCO*	
GI Bodyguard App [29]	Canada	Developed by CDHF*, supported by Rexall and Janssen	The app helps the patient to create the summaries with the HCP and their teams and aids in the following: a) Log bowel patterns, blood, pain, etc. b) Track medication, food and fitness. c) Create detailed reports and medical history.

*Note: CCFA-Crohn's and Colitis Foundation of America; ECCO-European Crohn's and Colitis Organization; CDHF-Canadian Digestive Health Foundation

Patient support program

A patient support program can be categorized broadly into two categories which are as follows:

A) Direct support includes services like drug delivery/injection information, telephone helpline, patient material/medical information, home care/nurse support, setting up the appointments, medication reminders, IBD magazines, nutrition tips and guidance to enroll in patient support groups [32].

B) Financial support includes patient assistance programs (PAPs), discount cards and co-pay cards offered by various pharma companies to improve access to costly IBD medicines. PAPs are offered by pharmaceutical companies to provide free or low-cost prescription drugs to qualifying patients (usually poor patients

having no or limited health insurance or prescription drug coverage) who cannot afford the high-cost medicines [33].

AbbVie's Patient Assistance Foundation, AbbVie Care, Takeda's Entyvio Connect Program, Johnson and Johnson Patient Assistance Foundation, Janssen's RemiStart Program, Tysabri ActiveAccess Financial Program, UCB's CIMPlicity and Shire Cares are some of the notable initiatives which offer direct and/or financial services to the IBD patients [33]. In general, patients can avail services if they are prescribed and enrolled in the programs if they are prescribed company's product.

TIPS for self-management of IBD

Self-management is a concept that can help patients suffering from chronic illness to manage their disease better. It focuses on educating

the patients to take responsibility to monitor and manage their disease effectively and lessen the impact of the illness on their day-to-day lives [18, 34]. As self-management training is an integral part of the clinical management of the IBD, few tips are mentioned below to apprise patients about the roles and responsibilities [4, 35]:

- Understand the disease and its symptoms
- Be proactive in communicating any concerns with your HCPs, family, and friends
- Be aware of the medications, dosing and their possible side-effects
- Be compliant and adherent to the treatment regimen as prescribed by the physicians
- Prioritize the symptoms you wish to address
- Follow a healthy diet and exercise within your limitations
- Avoid unhealthy habits like smoking, alcohol and stress factors
- Join patient community and leverage experiences from the fellow patients and share success stories to inspire others
- Stay optimistic and take control over the disease and your life

CONCLUSION

IBD can have a debilitating effect on the lives of the patients and the people around them. Living with IBD is quite a challenge wherein patients have to face physical pain and discomfort, in addition to the psychological (emotional) symptoms due to the embarrassing nature of the illness. With the prevalence of the disease increasing, it is extremely pivotal to generate awareness about the disease among the general public as well to empathize the situations of the IBD patients. Also, patient education and self-management skills can empower the patients to stand firm against the odds of the disease. The services/initiatives undertaken by the health care companies and patient associations across the globe can lead to a paradigm shift in bringing harmony to the lives of the IBD patients. Hence, timely support and well-informed knowledge about managing their disease can empower patients about being optimistic and taking control of their life despite the illness.

CONFLICT OF INTERESTS

The authors do not have any conflict of interest to declare

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