

Inflammatory bowel disease register: Steps towards Crohn's & colitis foundation of Saudi Arabia (CCFSA)

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Abstract:

Inflammatory bowel diseases (IBD) are among the leading cause of financial burden, morbidity and employee absenteeism in developed countries because of their chronic remitting and relapsing courses. IBD is estimated to affect the Canadian economy to the tune of 100 million dollars per year. The data regarding exact prevalence in Asian countries, including Saudi Arabia, is still incomplete as there is underreporting and lack of proper registry of the diagnosed cases. The prevalence of inflammatory bowel disease (Ulcerative colitis, Crohn's disease) has increased over the last decade in Saudi Arabia due to increased IBD awareness among population, as more patients seek medical help and also due to unknown reasons. There is a need of proper registration of IBD patients and establishment of Crohn's & colitis foundation of Saudi Arabia (CCFSA) as in other parts of the world. The Crohn's & colitis foundation of Saudi Arabia will be a forum which will coordinate IBD treatment and research in the country in addition to health education among IBD population.

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Introduction

Inflammatory bowel disease (IBD) is an idiopathic disease and occurs in genetically predisposed individuals. It is estimated that 1.4 million persons in the United States and 2.2 million persons in Europe suffer from these diseases.⁽¹⁾ Internationally the overall prevalence for IBD is 396 cases per 100,000 persons. Earlier IBD was considered to be more prevalent in West but now it is known to occur globally. Studies from different parts of Saudi Arabia^(2,3) have confirmed that the disease patterns are almost similar to those in other parts of the world with one hospital based study showing an increase in its incidence.⁽⁴⁾ An epidemiological study could unravel even large number of cases who either don't seek medical attention or follow alternative treatments. To address this issue there is a need to develop a system so that these patients are registered properly and managed scientifically. This requires enrolment of all IBD patients and establishment of **Crohn's & colitis foundation of Saudi Arabia (CCFSA)**. Such foundations already exist in Europe, USA, Canada, India Australia etc. Establishment of CCFSA will be a noble mission to estimate IBD burden in the country in addition to research.

Aims of Crohn's & Colitis foundation of Saudi Arabia (CCFSA)

1. Awareness of IBD in the community.
2. Registration of all IBD patients to constitute IBD data register.
3. Treatment guidelines & regular follow-up plans in accordance with international guidelines and based on local data related to patterns of exacerbation.
4. Rehabilitation of IBD patients in the society.
5. Development of a proper link between primary care physician and tertiary care centers.
6. Training programmes for primary care physicians.
7. Research.

Steps towards Crohn's & colitis foundation of Saudi Arabia (CCFSA):

1. Establishment of IBD Web Site:

Establishment of a comprehensive website of the foundation will constitute the first step in the process of development of CCFSA. We need to enroll all the inflammatory bowel disease patients based on a proforma and each patient should receive an IBD number for follow up.

Primary care physicians registered with the foundation should have access to the web site for the data entry. IBD data register of the country should be updated by all primary care physicians involved with IBD care on regular basis after each clinical encounter with IBD patient. Focus of the foundation will be to co-ordinate follow up plans between primary care physician and experts working in the tertiary care centers. This will help in the decentralization of IBD care and provide comfort to the patient.

2. Confirmation of the Diagnosis:

a) Before enrollment of the patients, a perfect diagnosis is mandatory as IBD diagnosis, at times, is challenging. Patients need to be examined thoroughly and the disease extent should be evaluated. In ulcerative colitis severity of the disease as described by Binder et al⁽⁵⁾ can be adapted. Ulcerative colitis patients should have their Mayo's score⁽⁶⁾ at initial presentation and whenever they undergo colonoscopic examination. The idea is to stratify IBD data for better management and future research.

b) Colonoscopic biopsy: Histopathological slides should be transported to the tertiary care center for second opinion and diagnosis confirmed by a pathologist having special interest in GI histology as these diseases are mimicked by various other disorders as well. A unified system of histological classification and scoring based on disease activity and chronicity scores, can be adapted as described by Gebos et al.^(7, 8)

All efforts should be made to distinguish abdominal tuberculosis from Crohn's disease (CD) and vice versa as tuberculosis closely mimics CD especially in an era of global epidemic of AIDS.

It is imperative to have all the base line investigations in these patients and keeping in

view need of corticosteroids and other immunosuppressants during the management, they should be screened for hepatitis B, HCV, HIV, diabetes etc.

An eye examination and Bone mineral density can go a long way to avert treatment related complications in this population.

3. Vaccination:

All IBD patients should be given Hepatitis B vaccine and other recommended vaccines no sooner the diagnosis is confirmed.

4. Nutrition:

Dietetics department should be involved for dietary advices in each center as IBD patients often undergo self dietary modifications which neither cause relapse nor any complication during the course of the disease. They remain undernourished due to these reasons in addition to protein losing enteropathy due to disease process per se.

5. Attention in special groups:

a) IBD during child hood and adolescence:

There has been an increased rate of incidence of these disorders due to high index of suspicion and prompt referral of patients to better centers. Studies have shown that most cases are now being diagnosed between 10 and 16 years and it accounts for 25% of all cases of IBD⁽¹⁰⁾.

Growth abnormalities following steroids treatment and disease process per se need special attention and advice of an endocrinologist or a pediatrician in this population is always warranted. Hence responsibility of the foundation will be to co ordinate a multidisciplinary approach in IBD management.

b) IBD during pregnancy and postpartum:

Studies have shown that IBD exacerbations are known to occur in the first trimester and patients with active UC at the time of conception often have continued problems throughout pregnancy⁽¹¹⁾. This emphasizes the need of a planned pregnancy among IBD patients in order to ensure a healthy baby and a healthy mother. Further patients need to be counseled regarding continuation of the

treatment during pregnancy and postpartum.

6. Follow-up:

Telemedicine facilities can help in proper follow up of patients living in far off places without discomfort of travel and expense to the patient after an initial visit to tertiary care center.

Ulcerative colitis patients may be followed up in accordance with the Clinical activity index⁽⁹⁾. These patients are known to have altered immunity primarily due to the disease process and also due to treatment so they need to be monitored for reactivation of tuberculosis and other opportunistic infections, thrombotic complications etc in addition to carcinoma colon.

Patterns of acute exacerbation in ulcerative colitis need to be looked into with the help of the primary care physician. The data generated can be pooled into the common web site of the foundation for patient management CME and research.

Various GI centers can be identified on national level for Carcinoma colon surveillance in UC patients so that colonoscopies are carried out regularly in accordance with the international guide lines.

7. Counseling and patient education:

Health education is the cornerstone in the management of any chronic illness including IBD. Every bloody diarrhea is not hemorrhoid or an infectious process; awareness needs to be generated among community so that there is a red alert whenever any person notices blood in stools especially in medically underserved areas of the country. Mass media /Religious places can be involved to increase the awareness of these chronic disorders and celebration of **Colitis day** on any suitable day of the year can strengthen this drive further on a national level. Seminars can be organized so that patient doctor relationship gets strengthened and patients are treated before complications bring them to medical attention.

After achieving an initial remission UC patients often stop treatment and later present with exacerbations or complications. Counseling regarding strict compliance to

treatment in UC is mandatory as treatment is known to prevent exacerbation and development of colorectal carcinoma. Patient should be given necessary literature for complete awareness of the disease and such information should be made available on the web site as well. Study from Australia has reflected that 40% of IBD patients take alternative medicine without any significant relief, the figures would be higher in developing countries.

8. IBD help line:

Enrollment of gastroenterologists and physicians with special interest in IBD should be made by the foundation so that a help line is developed for immediate help. Helpline should include central hospital emergency numbers and phone numbers of physicians interested to provide advice.

9. Ulcerative Colitis society:

IBD is very distressing and patients undergo lot of stress during their productive years. These patients, their spouses and parents need lot of emotional support during their school days, employment etc. IBD society comprised of a forum of diagnosed patients can help to boost the morale of newly diagnosed patients.

Web help entitled *I am happily living with the disease* based on information provided by educated patients to the website of the foundation can help newly diagnosed patients to accept the disease and treatment compliance.

10. Research:

Various training programmes, conferences and workshops can be organized for proper training of primary care physicians by the foundation at tertiary care centers of the country.

Epidemiological surveys need to be carried out to know the actual burden of these chronic disorders in the country. Cases coming to medical attention often reflect the tip of ice berg. Various biomarkers⁽¹²⁾ can be used for screening of IBD and for follow up to assess the disease severity and treatment response in a non invasive manner.

Research can be many fold ranging from genetic studies, host environment interaction and clinical trials involved in the treatment.

Foundation can identify various centers in the country for each trial.

11. Online journal of the foundation: *The Colitis journal*

A quarterly on line journal publishing various updates/latest researches regarding the disease for professionals and for the patients can strengthen IBD health education and research in the country.

12. Sponsorships:

Different foundations of the world have used number of ways to raise funds for their foundations as the foundation needs lot of funds to conduct and promote research e.g. Canadian colitis foundation have a budget of 80,000,000 dollars for the year 2008 and 100,000,000 dollars for the year 2010. Funds can be raised from pharmaceutical parties and voluntary donations etc. in Saudi Arabia in addition to official grants.

13 .Inflammatory bowel disease research enhancement act.

Last but not the least there is a need to involve Government organizations at all levels in the development of the foundation and to enact laws for promoting IBD research.

Conclusions:

Keeping in view the increased prevalence of inflammatory bowel disease in Saudi Arabia it is the responsibility of medical fraternity to stratify IBD data on a national level so that IBD management and research leaps into a new horizon. The Crohn's & colitis Foundation of Saudi Arabia (CCFSA) is the need of the hour and we all must work hard together to make it a success. This noble effort shall go a long way towards the betterment of IBD patient care and research.

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