## **EDITORIAL**





# Rapidly changing epidemiology of inflammatory bowel disease: Time to gear up for the challenge before it is too late

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Inflammatory bowel disease (IBD) has become a significant global health concern affecting > 0.3% of the world population [1]. While the disease prevalence in India may be lower compared to western countries, the country's vast population of over 1.428 billion translates into a large number of individuals affected by IBD [2].

The article by Dharni et al. in this *Issue*, "Trends of inflammatory bowel disease from the Global Burden of Disease Study (1990-2019)," sheds light on the evolving trend of IBD and provides crucial insights into its burden on a global, regional and national scale in 204 countries [3]. The authors need to be congratulated for their efforts to extract the data on IBD from complex data of original study.

# **Global burden of IBD**

The above-mentioned study, which utilized the comprehensive Global Burden of Diseases, Injuries and Risk Factors Study (GBD) 2019 dataset, presents an analysis of IBD trend over three decades [4]. From 1990 to 2019, the number of people living with IBD surged from 3.3 million to 4.9 million, illustrating the increasing disease burden, with the attendant consequences on care of these patients [5]. Notably, although the crude global prevalence of IBD rose during this period, the age-standardized global prevalence showed a decline. Age-standardized rates provide a better comparison between populations with different age structures. A similar earlier study, "The global, regional and national burden of inflammatory bowel diseases in 195 countries and territories, 1990-2017," published global burden of diseases, injuries and risk factors from 1990 to 2017 [6]. The IBD part of

As against previous data, China has the maximum number of cases, followed by the United States of America (USA) (911,405 and 762,890, respectively) [5].

# Trend in global burden of disease

According to GBD 2019, the global incidence has decreased and the prevalence of IBD increased from 1990 to 2019 with regional variations: in North America (high disease burden area), there is a plateauing or decreasing trend, whereas Asia, some parts of Africa, Middle East and part of Latin America showed increasing trend.

Two previous studies looked at time-based incidence and prevalence based on systematic review. Molodecky et al. reviewed 260 studies from 1950 to 2010. Since 1950, 75% of Crohn's disease (CD) and 60% of ulcerative colitis (UC) studies showed increase in the incidence of IBD [8]. Since 1980, 56% of CD and 29% of UC studies showed increasing incidence. A significant decrease in the incidence of UC was reported only in 6.0% of studies (three studies) and none for CD. They concluded that the incidence of IBD is increasing or stable in virtually every region of the world that has been studied. Second study, by Ng et al., reviewed 147 studies from 1990 to 2016 [1]. Of the studies which looked at incidence, 16 of 22 (72.7%) studies on CD and 15 of 18 (83.3%) studies on UC reported stable or decreasing incidence of IBD in North America and Europe. On the other hand, incidence has been rising in newly industrialized countries in Africa, Asia and South America.



this study was published later, in 2020 [7]. According to this study, there were 6.8 million (95% uncertainty intervals 6.4-7.3) cases of IBD globally. The number has dropped drastically to 4.9 million in 2019 GBD study after correcting the methodology. This discrepancy is related to improved specificity of case definition using ICD codes: IBD was defined according to the 10th revision of the International Classification of Diseases (ICD-10) codes [4]. There were other factors as mentioned by the authors for this discrepancy.

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From these studies, it is clear that the burden of IBD remains high in western countries due to more years lived with disability, but the incidence seems to be stable or decreasing, whereas incidence is increasing in newly industrialized areas and disease burden is low in these countries at present.

The GBD study showed an increase in the total number of deaths but the age-standardized death rate has declined, reflecting advances in healthcare and disease management. The shift towards more years lived with disability (YLD) and fewer years of life lost (YLL) signifies improved care and an increased focus on enhancing patients' quality of life.

## Indian scenario

An important aspect of this article is the data on Indian patients with epidemiological trends of IBD in India. The GBD study estimated the number of IBD patients to be 2.7 lakhs (0.27 million), which increased from 1.3 lakhs in 1990. Age-standardized incidence rate increased but age-standardized prevalence rate decreased (which is surprising). Total number of deaths increased from 2770 in 1990 to 4214 in 2019 but age-standardized death rate decreased.

Are the figures of disease burden representative of reallife scenario in India? In clinical practice, we seem to be seeing a larger number of new patients with IBD. A previous estimate of IBD population in India placed the figure at 1.4 million in 2010, which was only second to IBD diseases burden of 1.6 million in the US. The figure of 2.7 lakhs may represent an underestimation of IBD patients in India. The GBD 2019 Study collected data from censuses, household, civil registration and vital statistics, disease registries, health service use, satellite imaging, disease notifications and other sources. Many of these sources are not available in India. So, it is likely that there may be a role for assumptions or model inputting, while estimating the low disease burden in India. It also undermines the need for studies from this country.

Till date, only two population-based studies have investigated incidence and/or prevalence of UC in India [9, 10]. The initial study, conducted by Khosla et al. in 1984 in Haryana, north India, encompassed 21,971 participants and observed a prevalence of 42.8 UC patients per 100,000 individuals [9]. A second study, carried out 15 years later by Sood et al. in Punjab, utilized a cluster sampling method and calculated age-standardized prevalence rates after screening a population of 51,910 individuals [10]. In this study, a total of 23 patients were diagnosed with UC, resulting in a prevalence rate of 44.3/100,000. Subsequently, the incidence was calculated during a follow-up visit to the same region one year later and was reported to be 6.02/100,000.

When comparing incidence and prevalence rates with other Asian countries, Indians have highest incidence and prevalence of IBD [11]. Population-based studies to determine the incidence and prevalence of Crohn's disease (CD) are currently unavailable. In a prospective study in 13 countries of Asia Pacific region, incident cases of IBD were enrolled and the incidence was calculated by number of patients and total at-risk population in the pre-defined catchment area [12]. The mean annual incidence in (South) Indians was 3.91 (95% confidence interval [CI] 3.31–4.57/100000 population) for CD and 5.40 (95% CI 4.70–6.18/100000 population) for UC. These studies shed light on epidemiology of IBD in India.

# Challenges and the way ahead

With the significant disease burden of IBD in India, we need to gear up to face the challenges of managing large number of patients. This can be done on two fronts: tackling the explosion of the disease and taking definitive steps to prevent the disease.

## Tackling the high disease burden

#### Early diagnosis and institution of right treatment

Although the diagnostic delay can vary from two months to eight years, a recent review suggested that the delay in diagnosis of UC ranged from two to six months and that for CD was two to 12 months [13]. Diagnostic delay can lead to adverse outcomes such as poor response to medical therapy and increased need for surgery [14, 15]. Two studies from India have showed that prior anti-tuberculous therapy is a risk factor for stricture formation in CD [15, 16]. A colonoscopy two to three months after initiation of anti-tuberculosis therapy should reduce this delay and complication. Awareness among family physicians and internist as well as surgeons will help in reducing diagnostic delays. Timely initiation of immunosuppressive and biologic therapy will reduce the disease complications. Cost of the therapy, especially the biologic agents, is prohibitively expensive. Health insurance coverage is low: 50% of healthcare expenses in India are paid out of pockets (global average is 20%) and one in four urban households take loans to cover medical expenses [17–19]. Government schemes have the potential to cover up to 70% population, but the coverage may not be adequate [17].

## **Preventive aspect**

It is imperative to start preventive measures to reduce future burden of IBD, at individual gastroenterologist's level, society (Indian Society of Gastroenterology) level



and government level. Some of the measures include avoiding antibiotics in children as well as adults, stopping smoking and campaign for healthy diet (low dietary intakes of total fat, particularly animal fats, refined sugars, meat and increase in intake of fruits and vegetables). These will go a long way in preventing environmental triggers for IBD.

In conclusion, the article "Trends of inflammatory bowel disease from the Global Burden of Disease Study (1990-2019)" fills a crucial knowledge gap in the field of IBD epidemiology. By addressing the evolving trends and disease burden, the study facilitates evidence-based decision-making to improve patient care, advocates for resources management and policy frameworks on a global scale. As researchers and healthcare practitioners continue to grapple with the challenges posed by IBD, studies like this are vital stepping stones towards a better definition of disease and also for taking steps towards a future with better outcomes and improved quality of life of IBD patients. We must start working on preventive aspects of the disease. It also undermines the need for research from India.

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