National consensus on inflammatory bowel disease in India—an initiator's perspective

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The publication in this issue of the *Journal* of national data on inflammatory bowel disease (IBD) and guidelines drawn by Indian experts on how to manage it in the subcontinent [1, 2], given our unique settings and challenges, marks a milestone in the efforts of the gastroenterology community of this country to confront and recognize this disease that we all now commonly encounter in practice, but have in the past shied away from examining comprehensively.

It all started in the early 2000's when I had just taken over as the Honorary Secretary of Indian Society of Gastroenterology (ISG) and had been invited to deliver a talk on "IBD—the national scene" at a theme-conference in Manipal. A cursory search of PubMed, by way of preparation, revealed embarrassingly few reports and publications from this country, despite the entity being in existence for several decades and increasing rapidly in frequency in the clinic in recent times.

Even though the number of IBD patients in India was estimated to be more than a million, and our Indian Society of Gastroenterology then comprised one thousand members, there was paucity of data from different parts of the country and no attempt to pool them to provide a national picture. Also, in spite of a high frequency of infective conditions in India that mimic IBD, there had been no serious attempt to get senior specialists practicing here to sit together and draw up consensus statements or practice guidelines that would help address our unique concerns and challenges while treating our patients here.

Publishing has always been the Achilles' heel of Indian scientists, but our performance in the field of IBD fared even

worse. Of around 18,000 publications on IBD in humans over the last 10 years, only 164 (0.9 %) were from India, and were equally meager for both ulcerative colitis (87 of 8,000, 1 %) and Crohn's disease (93 of 11,000, 0.9 %). Further, there had been no "national" data or "national guidelines" that could help Indian doctors manage their patients in this region.

The ISG in 2003 therefore embarked on a challenging mission to collect data systematically from all across the country on four common diseases that we encountered in our clinics, and yet had no national figures to quote. Dr Philip Abraham, the then President of the society, and I, the then Honorary Secretary, initiated four "Task Forces" to study irritable bowel syndrome (IBS), gastroesophageal reflux disease (GERD), IBD, and diarrhea. Reports of the first two have already appeared in this journal.

In the backdrop of overwhelming skepticism, as all such past attempts at multi-centric collaborative studies in India had crashed to whimpering ends, we put in much discussion and thought into creating these Task Forces. Philip and I also often argued whether time was worth spending in collecting multi-centric data, a long, fragile and painstaking process fraught with the hazard of fizzling out before completion, or jump into the modern fray of drafting guidelines based solely on clinical experience of eminent specialists. We finally settled for both.

The next difficult task was to find the right team to take this venture forward. Our wish list featured a young yet mature, scientific minded yet pragmatic, and uniformly acceptable member to serve as the national coordinator, and one or two senior members with a proven track record of research and publication, to chair. Dr Govind Makharia's profile matched our dream coordinator's, while two senior academics with vast experience in IBD, Prof B S Ramakrishna from Christian Medical College, Vellore and Dr Philip Abraham from Mumbai, agreed to spearhead it.

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Our next main challenge was to get representative data from all across the country. IBD patients, especially the ones with severe disease, usually find their way into large tertiary-care institutions and into their databases. Pooling data from a handful of such departments would have been easy and quick, but would have provided a skewed picture. We therefore put up an invitation on the website of the ISG and in its publication, the Indian Journal of Gastroenterology, inviting interested members to join in and took care to ensure that there was representation not just from all regions of the country but from all strata of health-care delivery, that is from secondary-care institutions and private practice as well.

No such major national academic activity can occur without adequate financial support. Sun Pharmaceuticals came forward with a generous grant and provided, in addition, logistics and networking help to ensure success for this venture.

There were still a few more hiccups down the road. Some regional groups and foundations, comprising senior specialists who had dedicated themselves to the care of IBD patients, perceived the Indian Society of Gastroenterology's initiative as a competitor and threat. Some opposed it and many initially stayed away. It required hours of discussions to allay their concerns and persuade them to get on board.

Over the 9 years that this exercise has taken us, I often remembered the fable of the "Hare and Tortoise" from Aesop, and wondered if the latter would make it to the finishing line at all some day. The other task forces had darted off more sprightly; the one on IBS published its report in 2008 [1] and the GERD task force in 2011 [2]. And after an inordinate delay that now seems acceptable we have the tortoise reaching

the finish line with 2 publications in its basket: its report, and consensus statements and guidelines! [3, 4].

I can look back with satisfaction that we now have Indian data on 3 common disorders that provide a framework for further multi-centric collaborative work. Younger generations of gastroenterologists from this country will now have our own data to quote. And India will not appear as a dark space in the epidemiologic world map on these three disorders.

Indian gastroenterologists have now finally emerged on a path that emboldens them to work in teams, generate multi-centric data that can represent the region, develop their own consensus on sticky issues and chart out their own practice guidelines, as they have done for IBD. The destination is far but we have at least found the road.

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