IBD REVIEWS

Scientific and technological research article

Title: The Increase of IBD in Latin America: Challenge or Opportunity?

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Abstract

The global increase in incidence and prevalence of inflammatory bowel diseases (IBD) includes Latin America, where this trend has already been identified in some of its countries. Childhood IBD is also increasing, showing a higher incidence of Crohn's disease (CD) over ulcerative colitis (UC). Current healthcare systems are not prepared for handling this complex, lifelong costly disease that impacts multiple aspects of the patient's life. The transition from pediatric to adult care in children with chronic diseases is accompanied by risks of loss of continuity and decreased adherence to medications and is best addressed by structured longitudinal transition processes. Integrated interdisciplinary models dedicated to caring for patients with IBD in other areas of the world have shown improvement in outcomes and cost reductions. Incorporating pediatric care into the specialized IBD center would serve this purpose. Latin American countries facing an increase in IBD may benefit from pro-actively developing these integrated IBD centers within their healthcare systems.

Keywords: Inflammatory bowel disease, Latin America, integrated care, transition pediatric care, IBD medical home.

The incidence and prevalence of inflammatory bowel disease (IBD) continue to rise across the world. These increases have been reported in all ethnic and racial groups and in countries where IBD was rare or infrequent [1,2,3]. Newly industrialized countries appear to have the highest rate of increase.

Latin American countries are among those with recent industrial development. Incidence and prevalence of IBD are in the low-rank range [1]. A systematic review of IBD in Latin America by Calderón et al included 25 studies from 2000 to 2015 [4]. The reported incidence for ulcerative colitis (UC) ranged from 0.74 to 6.76/100,000 person-years, whereas for Crohn's disease (CD) it ranged from 0.24 to 3.5/100,000 person-years. The prevalence for UC was 0.99 to 44.3/1000,000 and 0.24 to 16.7/100,000 for CD. The main data for calculating incidence and prevalence in this study was generated from studies in Brazil, Uruguay, Barbados, and Puerto Rico. Data on treatment, hospitalization, mortality, and outcomes were collected from publications for Colombia, Argentina, Chile, Cuba, Mexico, Brazil, and Puerto Rico. The authors conclude that although the burden of IBD appears to be important in Latin America, there is a need for more and better studies using standard definitions and representative samples. A study describing the incidence and prevalence of IBD in midwestern Sao Paulo, Brazil, reports a prevalence rate of 0.99/100,000 for UC and 0.24/100,000 for CD between 1986 and 1990, which rose to 14.81/100,000 for UC and 5.65/100,000 for CD between 2001 and 2005 [5]. A second study from Piaui in Northern Brazil reports an annual index occurrence rate of IBD that rose from 0.08 to 1.53/100,000 from Jan 2011 to December 2012 and noted an increase in frequency in the area over the last two decades [6]. UC was predominant in the study population. A single-hospital study from Mexico noted a 2.6-fold increase in hospitalizations for IBD from 28.8 to 76.1/100,000 over 20 years (1987 to 2006) [7]. Although CD was infrequent, a four-fold increase in hospitalizations was detected. Barbados, a tiny island in the Caribbean with a high human development index and a population of mostly African origin has also reported a trend of increasing incidence, both for UC and CD [8]. A retrospective, registry-based study from Uruguay for 2007 to 2011 showed an adjusted IBD incidence of 5.22/100,000 person-years, UC being much more common [9]. Although this was considered a low incidence rate, it is noteworthy that the incidence was higher for ages 20 to 44 (9.12/100,000), followed by those 19 and under (3.45/100,000). These numbers will impact significantly the prevalence of IBD in the subsequent decades.

Global studies suggest that the incidence of IBD is highest in the pediatric population [10,11,12]. Although IBD in Latin America has been reported mainly in the adult population, a one-year prospective multi-center pediatric IBD registry in Argentina was published in 2017 [13]. Fifty children with IBD, of which 20 had CD, were described. The mean age at diagnosis for UC and CD were 9.4 and 9.7 years respectively. A study of the prevalence of IBD in Puerto Rico for 2013 showed an overall prevalence of 181.54/100,000, with a 3-fold increase among the pediatric population, in which a prevalence of 89.8/100,000 for IBD, 60/100,000 for CD and 21.1/100,000 for UC was found [14]. Unexpectedly, a significant number of very young children, most with CD, were identified, a finding already noted in Canada [11].

It appears evident that a rise in the incidence and prevalence of IBD is occurring in Latin America, and an increase in pediatric IBD is to be expected as well. The burden that this chronic and complex disease imposes on the health system and the economy is well recognized. Proposals to reduce the incidence of IBD in the world have been suggested to prevent the escalating prevalence in newly industrialized countries [2]. While that "moonshot" is appealing, developing successful models for the healthcare of patients with IBD within our current resources is an important priority.

Integrated care

The integration of health services is driven by demographic and epidemiological changes, expectations and rights of the population, the development of medical and information technologies and economic pressures [15]. The following definition has been suggested by the WHO European Office for Integrated Health Care Services: "Integrated Care is a concept bringing together inputs, delivery, management, organization of services related to diagnosis, treatment, care, rehabilitation, and health promotion. Integration is a means to improve the services concerning access, quality, user satisfaction, and efficiency” [16]. Integrated care programs for patients with chronic diseases such as congestive heart failure, diabetes, asthma, and chronic lung disease have been implemented for some time, and in general, have resulted in a decrease in the use of health resources, increased adherence to treatment, better patient-reported outcomes and improvement in quality [16].

Inflammatory bowel diseases are chronic complex conditions that impact multiple aspects of a patient's life. Besides the gastrointestinal manifestations, psychosocial aspects are foremost, including high rates of anxiety, depression and psychological stress. The role of psychosocial factors in disease manifestations, complications, response and adherence to therapy as well as quality of life have been documented [17,18,19]. Recognizing anxiety and depression in patients with IBD and managing psychosocial issues is essential in achieving optimal treatment goals. The involvement of other specialists in the care of these patients is therefore necessary. An integrated healthcare model is a way of addressing this need.

The IBD UK organization, a partnership of patient and professional organizations working together to improve the care of these patients in the United Kingdom, has developed standards for the care of patients with IBD [20]. The IBD service is the core of these standards. The composition and aspects of the IBD service are detailed on their website and can serve as a guide for developing this specialized service.

Two important publications from Australia document the implementation of an integrated model for IBD and its impact on costs and utilization [21,22]. A formal IBD service was introduced in 2008 for all in- and outpatients with IBD at the Royal Adelaide Hospital [21]. This IBD service includes dedicated gastroenterologists, a specialty IBD nurse, a weekly designated clinic, a joint medical-surgical clinic, and a regular radiology review. Two cohorts of IBD patients, before and after the implementation of the IBD service (IBDS) were compared. Similarly, the post-IBDS cohort was compared to an age and gender-matched control group (non-IBD). The number of admissions per patient was lower in the second IBD group (IBDS) as compared to the first. Also, the number of admissions and inpatient costs in the IBDS group versus a control group (non-IBD) were lower in the second cohort. Mikocka-Walus and her group developed a biopsychosocial model of care at the Royal Adelaide Hospital [22]. The implementation of the model included collecting epidemiologic data on mental health co-morbidities, raising awareness of mental health problems and evaluating the effects on patient outcomes. They were able to document a high rate of anxiety (36%) and depressive symptoms (13%) and a higher rate of hospitalization in this group. Cognitive-behavioral therapy resulted in improvements in disease activity, anxiety, depression, quality of life and coping. Less use of opiates, lower hospitalization rates, and reduced mean total cost of inpatient care were also seen in the treated group versus the controls [22].

An international group of IBD health professionals recruited through the European Crohn's and Colitis Organization, Australia IBD practitioners' network, UK and Australian IBD nursing networks, Canadian IBD practitioners and other IBD experts were surveyed on their current care models and their views for change [23]. Over half (54%) considered their IBD service an integrated care model, 65% included standard mental health assessment, and 51% believed the IBD service should be managed in specialist-led clinics. This study concluded that an ideal IBD service should be fully integrated, with significant roles for nurses, psychologists and dietitians, run in specialist clinics, be accessible to patients, and, not surprisingly given the countries of the surveyed population, be publicly funded.

In the United States (US), these integrated models are called medical homes. A medical home can be defined as "a model or philosophy of primary care that is patient-centered, comprehensive, team-based, coordinated, accessible, and focused on quality and safety" [24]. It is a prominent component of the Affordable Care Act, a comprehensive health care reform law enacted in 2010. Initially meant to be for primary care, medical home models have been created by various specialty societies including the American College of Physicians, the American Academy of Family Physicians, the American Academy of Pediatrics and the American Medical Association. Recognizing that specialists may provide the principal care of some patients with chronic conditions, the Center for Medicare and Medicaid Services defined primary care as "the provision of integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practicing in the context of family and community" [25]. Developing this concept for IBD was the logical next step. Regueiro and his group at the University of Pittsburgh Medical Center (UPMC) have been the leaders in the United States in establishing a formal well-structured IBD Medical Home that enrolls patients with complex IBD who are high resource users (more unplanned visits to the Emergency Department, hospitalizations and diagnostic testing) [26.27]. The UPMC IBD medical home, called the UPMC Total Care-IBD, includes a BESST CARE approach (Behavioral, Social Stress Training care) for the more than 50% of patients with pain, stress, difficulty in coping, anxiety, depression, and fatigue. Clinical care pathways, joint gastroenterology-surgery meetings, drug utilization strategies, preventive care, nutritional counseling, telemedicine and virtual technology, patient satisfaction surveys, and peer support are integrated into the model [26]. The UPMC Total-Care IBD program was able to demonstrate a decrease in unplanned care and disease activity and an improvement in the quality of life in the patients enrolled in their medical home [28].

The fact that integrated patient centered IBD care has been implemented within varied healthcare models, public and privately funded, suggests that the concept can be developed globally, adapting it to the specific economic and healthcare characteristics of the local systems. The Center for Inflammatory Bowel Diseases of the University of Puerto Rico is one example. Ours is a mixed healthcare system that includes both private and government-funded individuals, in a struggling economy. Led by gastroenterologists expert in IBD, our Center provides care for adult patients and transitional care for complex pediatric cases with IBD in an academic environment. During the visit to the dedicated IBD clinic, psychologic support and nutritional education are offered. Patients in whom surgery for IBD is being considered are seen jointly with the surgeon. An enterostomal nurse volunteers her services for ostomized patients. Referral mechanisms to other specialists with an interest in IBD-related issues in the fields of gynecology, dermatology, rheumatology, and ophthalmology among others have been established. A close working relationship with radiology and pathology for many years assures interdisciplinary discussion of cases. A patient navigator is in charge of scheduling and is also is the liaison between the patient and the medical staff or other services. Management protocols are based on evidence, and procedures and medications are judiciously used. Ours is a teaching clinic that serves as a training site in interdisciplinary care for health professionals and provides continuity of care. There is access to physicians for urgent needs and the patients are seen expeditiously when in the Emergency Department. Though we have not been able to establish the economic model of the US-based Medical Home, we have developed an integrated patient centered IBD service unique in the island that offers high-quality care to the sickest patients in Puerto Rico.

Transition process from pediatric to adult care

The predicted increase in the incidence of IBD in children living in Latin America will result in an overall increase in the prevalence of IBD, impacting the healthcare system at multiple levels. Children with IBD present with more extensive and severe disease [29,30] and Crohn's is more prevalent than UC [29,31]. The disease is often refractory to medical treatments, which are also more limited in children, and not easily amenable to surgery. Childhood-onset IBD interferes with growth, education, psychosocial and sexual development [29]. As these children become adults with IBD, employment and economic productivity are affected. Current healthcare systems are not prepared for this snowball effect.

Pediatric care is different from adult care in many ways. Notable among these is the evolution of the patient from having an adult responsible for his care to becoming the decision-maker. This transition has been defined as the "purposeful planned movement of adolescents and young adults with chronic conditions from child-centered to adult-oriented health care systems" [32]. The American Academy of Pediatrics, American Academy of Family Physicians and American College of Physicians have stated that the goal of transition is to "maximize lifelong functioning and potential through the provision of high-quality developmentally appropriate healthcare service that continues uninterrupted as the individual moves from adolescence to adulthood" [33]. The National Institute for Health and Care Excellence of the United Kingdom (NICE), has published a guideline detailing recommendations, implementation and areas for research in the transition from children to adults' services [34].

Experience with transition processes for children with type 1 diabetes mellitus [35,36], organ transplantation [37], juvenile arthritis [38], and cystic fibrosis [39] supports the establishment of these processes in children with IBD. Although a transition process for adolescents with IBD is far from an established standard, advocacy and recommendations for implementing this process are growing [32,33,34,40]. Patients who transfer to adult care without a transition process are more likely to miss clinic visits and not comply with therapy. The need for surgery and hospital admissions has also been noted to be higher in these patients [41].

The stages of adolescence are not fixed in time, and developmental milestones will be reached at different ages for each individual. The transition process should, therefore, start in early adolescence and end with the final transfer to adult care when the patient is ready. It incorporates gradual changes in knowledge, attitudes, and behavior. The process must involve multiple stakeholders: the patient, the parents or caretakers, pediatric and adult healthcare providers, and the multidisciplinary staff involved in some way in the care of the patient. Psychosocial support, education about the differences in pediatric versus adult care, disease-specific knowledge, development of independence and self-advocacy, opportunity to meet the adult provider before the transfer, and participation of the parents support the success of the transition [19,20]. Proactive communication between the pediatric and adult gastroenterologists and the availability of solid medical documentation are essential. Checklists for the patient and the physician provided by the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) [40] and detailed steps published by Menon et al [30] are useful guides for achieving a good transition. The British Society of Gastroenterology has also published guidelines for the transition of care in children with digestive disorders [42].

Conclusion

It is expected that the incidence and prevalence of IBD in Latin America will continue to rise in the next decade, with a shift from ulcerative colitis to Crohn's disease. A significant proportion of new cases will be in children, who will become adults with IBD. Integrated interdisciplinary care for IBD has shown benefits in reducing costs associated to hospitalizations, improving outcomes and quality of life. We propose that the healthcare systems in Latin America develop models of integrated care, preferably incorporating pediatric care into their services. In such a setting, the transition of care can occur seamlessly within the IBD medical home. Having the infrastructure in place to care for a growing number of patients with complex IBD should facilitate the implementation of management protocols, performance of quality evaluations, and cost containment measures while providing care of excellence and improving the quality of life of patients with IBD. Additionally, alliances for research can be more effective in generating quality data and furthering knowledge of IBD in Latin America. This structured model may also serve as motivation for young healthcare professionals interested in the challenge of transforming healthcare while caring for the sick.

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