# Epidemiological study of inflammatory bowel disease in Cuban children and adolescents (Multicenter Study)

Trini Fragoso Arbelo<sup>a1</sup>, Elsa García Bacallao<sup>1</sup>, Waldimiro García Pérez<sup>1</sup>, Maria Elena Trujillo Toledo<sup>1</sup>, Emilio Rodríguez Ramirez<sup>1</sup>, Eduviges García Soto<sup>1</sup>, José Rústelo Aguila<sup>1</sup>, Raquel Toledo Padilla<sup>1</sup>, Rey Ramos Riera<sup>1</sup>, and Elvira Borbolla Busquets<sup>1</sup>

<sup>1</sup>Hospital Pediátrico Borrás-Marfán, Servicio de Gastroenterología y Nutrición. Facultad de Ciencias Médicas Manuel Fajardo. Universidad Médica de La Habana, Cuba

Inflammatory Bowel Diseases in children are not so infrequent and a high level of suspicion should be maintained in order to achieve an early diagnosis and maximum avoidance of complications.<sup>b</sup>

Inflammatory bowel diseases (IBD) are chronic inflammatory processes with periods of activity, alternating with others of latency, with a wide variety of digestive and extra-digestive manifestations. Its etiology is unknown at the present time, having implicated in its etiopathogenesis various exogenous factors that would interact on an organism with a certain genetic predisposition [1–3]. When we talk about IBD, we refer to two well-defined entities: Crohn's disease (CD) and ulcerative colitis (UC), which differ basically by the location of the lesions. In UC, only the colon is affected, while in CD it can affect from the mouth to the anus. The histological alteration affects only the mucous layer in UC, and is transmural in CD. In approximately 15% of patients at the onset of the disease, it is not possible to determine whether it is UC or CD and they are provisionally called indeterminate colitis [1]. Epidemiological studies on IBD in children are limited, however in 1999 published data referred an incidence in children and adolescents of 2.2 to 6.8 per 100,000 [4]. The general incidence of CD in the population is 5.3 per 100,000; for adolescents ages 15 to 19 it is 16 per 100,000; and for those under 15 years of age, 2.5 per 100,000. The incidence of UC in adolescents under 20 years of age is 1.5 - 2 per 100,000 in Scotland and in the non-Latin part of America. In adults it affects 50 - 75 per 100,000 inhabitants. Data are lacking in children [3,4]. The aim of this study was to determine some clinical and epidemiological characteristics of these diseases, the time of evolution at the present time, and to estimate mortality in children and adolescents diagnosed before the age of 19, in the last two decades, throughout the country.

## Methods

To know the frequency of IBD diagnosis in our country, a survey was designed and sent to the different Pediatric Gastroenterology departments to include all patients diagnosed before the age of 19, with clinical, endoscopic and histopathological diagnosis of UC and CD in the last 20 years. This survey included the following variables: general data, age at diagnosis, family pathological history of IBD, forms of presentation, location of the disease, in UC the degree of endoscopic

activity, time of evolution, complications, and estimating mortality. Subsequently, the medical records were reviewed in order to obtain the requested data.

### Results

Eighty eight patients between 6 months old and 19 vears old were reported; 73 (83%) with UC and 15 (17%) with CD. The most frequent age at diagnosis was between 10-14 years old, with a slight predominance of males in UC and females in CD. No family history of IBD was reported. The predominant form of presentation in UC was rectal bleeding (47.9%) and in CD it was abdominal pain (53.3%); perianal disease was observed in 46.6% of all cases of IBD. In UC, the most frequent location was pancolitis and grade III endoscopic activity; in CD the predominant location was ileocolic. Surgery was necessary in 46.6% of patients with CD and in one patient (1.3%) in UC. Hepatic complications represented 9.5% in UC. For all IBD patients, 33% were diagnosed in the last 5 years. Mortality was 4.1% for UC and 6.1% for CD.

# Discussion

Although epidemiological studies on IBD in children are limited, almost all have suggested that the incidence (number of new cases in the population per year) is similar to or greater than that found in the adult population. In Spain the incidence is between 0.8 and 1.8 per 100,000, lower than in other European countries with urban predominance [3]. It is currently known that the percentage of patients who develop the symptoms of these diseases during childhood and adolescence ranges between 25 and 40%. Our study showed 83% UC and 17% CD among Cuban children and adolescents suffering from IBD; in almost all countries the former is found more frequently than the latter, although it is suggested that these prevalence proportions may vary according to the geographical area studied. The distribution for the age of onset is bimodal with a peak between the second and third decade and a second peak between the fifth and sixth decade, with the mean age of onset in childhood between 11 and 13 years old and 5% earlier is reported of the 5 years, which corresponds to our results; Although rare in children under 2 years of age, there are cases described in infants, as reported in our series coinciding with other authors [3,5]. It is argued by most authors that there are no differences regarding sex in these diseases. It has been shown that there is a family aggregation among first degree relatives of up to 20 to 25%, but we did not find this background in our study. In studies conducted in UC, symptoms of rectal bleeding with diarrhea and weight loss predominate, while abdominal pain, growth retardation and diarrhea predominate in CD, which is consistent with our results. Perianal disease occurs in 30% to 50% of children and adolescents with CD [3], so omitting inspection of the perianal area in a child or adolescent with chronic gastrointestinal symptoms may delay the definitive diagnosis of CD. Nutritional alterations [6,7] are a form of presentation of these diseases, especially in CD in more than 30%, so a correct nutritional evaluation should not be omitted as a suspicion of them. The most frequent location observed by us in UC was pancolitis and activity grades II and III, in agreement with most of the authors. Around 60% of children with CD have ileocolitis and 20-25% have isolated ileal disease, agreeing with our results despite the small sample [2,3]. In recent years there has been an increase in the number of patients with IBD, coinciding with a higher index of suspicion and the greater availability of endoscopic studies [1-3]. which is observed in our study where the two thirds of the patients were diagnosed in the last 10 years and of them a third in the last 5 years. CD presented a predominance of surgical complications and UC predominated liver complications, which may even precede gastrointestinal symptoms [4,8] Although we know that collectomy in UC provides the only cure and it is accepted that the most appropriate surgical technique is ileoanal anastomosis with rectal mucosectomy and ileal sac formation, the inflammation of the ileal sac is a common problem. The indications for surgical intervention in UC are related to the appearance of dysplasia. It is stated by many authors that collctomy in children with UC has decreased significantly, a change that undoubtedly reflects improvement in medical therapies: nutritional support, broad-spectrum antibiotics and immunosuppressants, in addition to annual colonoscopic surveillance avoiding prophylactic surgery. Approximately 50 to 75% of children with CD require surgical intervention in the first 10 to 15 years after diagnosis. The main reasons for surgery are most often symptoms resistant to medical treatment and corticosteroid toxicity. Patients with ileocolitis have a recurrence rate of 70% over 5 to 10 years, compared with 15% for those with colitis alone [2]. Mortality in our series was related to liver diseases and complications during surgery. No case of colon neoplasia was reported as a complication

in our patients. It is concluded that IBD are not so uncommon in our environment and that a high index of clinical suspicion must be had to make an early diagnosis and it must be followed by a multidisciplinary team with special attention to educating the child or adolescent and the family regarding the disease process, its complications and those related to treatment.

We would like to thanks all the Pediatric Gastroenterologists of the Pediatric Gastroenterology Services in the country for the collaboration provided to carry out this multicenter study.

## Notes

- a. Email:fragoso@infomed.sld.cu
- b. Original version of this article is Ref [9]

### References

- [1] Kirschner, B.S, Ulcerative Colitis in children, *Pediatric Clinics North America*, **43** 1 (1996) 235-254
- [2] Hyams, J.S., Crohn's Disease in children, *Pediatric Clinics North America*, **43** 1 (1996) 255-277
- [3] Polanco Allue, I., Enfermedad Inflamatoria Intestinal, Temas de Pediatría, Bilbao, Spain (1999)
- [4] Andres, P.G. and Friedman, A.P., Epidemiology and the natural course of inflammatory bowel disease, *Gastroenterology*, **28** (1999) 255-281
- [5] Gonzalez, M., Vera, J.F., Avila, R., Colitis ulcerosa en un lactante, Rev Chil Pediatr 66 1 (1995) 40-43
- [6] Motil, K.S., Grand, R.J., Davis-Kraft, F., Ferlic, L.L. and Smith, E.O., Growth failure in children with inflammatory bowel disease: a prospective study, *Gastroenterology*, **105** 3 (1993) 681-691
- [7] Sagaro, E., Ruiz, A., Fragoso, T., Llanio, R. and Castaneda, C., Enfermedades inflamatorias crónicas del intestino en la infancia. Nuestra Experiencia, Rev Cub Ped, 56 (1984) 671-680
- [8] Ferguson, A., Assessment and management of ulcerative colitis in children, Gastrol Hepatol, 9 (1997) 858-863
- [9] Fragoso Arbelo, T., Garcia Bacallao, E., Garcia Perez, W., Trujillo Toledo, M.E., Rodriguez Ramirez, E., Garcia Soto, E., Bustelo Aguila, J., Toledo Padilla, R., Ramos Riera, R. and Borbolla Busquets, E., Estudio Epidemiológico de la Enfermedad Inflamatoria intestinal en niños y adolescentes (Estudio Multicentro, Rev Cub Pediatr, 74 3 (2002) 195-202