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Editorial

“...if you do not evaluate, you do not know...”, the importance of registries and audits



“...el que no evalúa, no conoce...”, la importancia de los registros y las auditorías

Inflammatory bowel disease (IBD) includes Ulcerative Colitis (UC) and Crohn's Disease (CD). Both are chronic diseases of unknown aetiology, with an increase in their incidence and prevalence observed worldwide. Knowledge advancement of this complex disease requires studies that include a sufficient number of patients, and to this end, systematic registries for data collection from unselected patients that reflect real clinical practice. These systematic registries also facilitate prolonged follow-ups over time, that lead to a better understanding of the disease's natural history and evolution, in addition to auditing our clinical practice, and the surgical technique outcomes used in treatment.

The ENEIDA project (Nationwide study on genetic and environmental determinants of inflammatory bowel disease) is a registry created in 2005,¹ comprising 80 hospital centres, including nearly 60,000 patients and has generated several scientific publications. The paper recently published in this journal by Sánchez-Guillén et al.² presents the first results of the REIC registry (Registry of Inflammatory Disease and Surgery), a registry of patients with IBD treated surgically, in which 77 centres participated and which contains the information of more than 1000 patients. As described in the registry, the volume of IBD patients treated surgically is dispersed over several centres, which means that the number of cases per hospital and surgeon is low. In a previous study carried out by the same group,³ it was already observed that the number of IBD surgeries per centre was not high and that there were no referral protocols to reference or specialised centres.

One factor that significantly impacts the outcomes of a disease treatment is the volume of patients treated per hospital. We have an example in ileal-pouch anal anastomosis (IPAA) surgery, where centralisation reduces postoperative complications and improves functional results in the medium and long term.⁴ According to this national registry, 31 IPAA were carried out in a period of 3 years, which contrasts with

the publication of a single Canadian centre that reported 758 IPAAAs over 11 years.⁵

As observed in the REIC, over 85% of highly complex interventions were carried out in higher volume hospitals and in 70% of cases, the procedures were performed by colorectal surgeons, presenting fewer postoperative complications.

It is difficult to determine the volume of interventions to be carried out to classify hospitals into high and low volume, since not many publications are available on this subject.⁶ High-volume centres were classified as those that performed more than 20 IBD interventions per year. A study in the United States considered high-volume hospitals to be those that carried out more than 160 IBD interventions,⁷ while a French registry defined high-volume CD hospitals as those that performed six or more ileocolic resections annually.⁸ In Canada, another study determined high-volume hospitals as those in which more than 12 colectomies were performed per year in the case of UC.⁹ These are examples of the difficulty in determining the minimum volume of interventions per centre to be classified as high volume hospitals.

The authors acknowledge that specific quality standards for IBD have not yet been implemented in Spain. One of these standards advises referring patients to specialised centres for more comprehensive care. Despite the absence of centralisation policies for IBD in Spain, the morbidity and mortality results of the REIC are similar to those reported by IBD reference centres.¹⁰ However, there is room for better research and possible improvements.

The quality of health care is also validated and strengthened through registries, and audits provide detailed and objective analysis of medical practice standards, ensuring the competence of specialised IBD units. An example is the existing national registries in countries such as Sweden, the USA and the UK.^{11–13} REIC is a voluntary registry, and despite the high participation, there is a lack of IBD reference hospitals, so it is difficult to confirm the absolute plausibility

of its results. Prospective registries at a national and international level should be part of clinical improvement programmes, aimed at maintaining quality standards and improving outcomes. The REIC is a first step in this direction at a national level. It may be added to other projects already underway. The CUE programme ("Certification Programme for Comprehensive Care Units for patients with Inflammatory Bowel Disease") endorsed by GETECCU¹⁴ or the Accreditation Programme for Coloproctology Units promoted by AECF/FAECP (Spanish Association/Foundation of Coloproctology)¹⁵ are examples of a commitment and responsibility towards IBD patients in Spain.

The diagnosis and therapeutic management of IBD is becoming an important health challenge. Greater understanding is required of the disease epidemiology; the effect of IBD on health and the social resources and available budget to adopt effective policies for prevention, and reduction of the IBD care burden. To achieve this, extensive and effective coordination of proposals and activities between scientific societies and the national health system is essential.

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