THE IMPORTANCE OF EARLY DIAGNOSIS IN INFLAMMATORY BOWEL DISEASE (IBD)

CROHN'S & COLITIS UK

INTRODUCTION

Inflammatory bowel disease (IBD) describes a group of gastrointestinal disorders, mainly Crohn's disease (CD) and Ulcerative colitis (UC), characterised by unpredictable and chronic inflammation with fluctuating periods of disease activity and remission.

During disease activity, patients often experience gastrointestinal symptoms. This significantly impedes quality of life due to the impact on daily activities, the ability to function in work and social situations, and on interpersonal relationships.

Currently in the United Kingdom, 0.81% (1 in 123) of the population are living with IBD,[1] the second highest IBD prevalence globally, after the United States.

Diagnosing IBD

Typical symptoms include:

- Gastrointestinal symptoms (GIS) including abdominal pain/ cramping, bloating, wind.
- Diarrhoea/constipation (including blood or mucus in stools), and urgency.
- Reduced appetite, malnutrition and weight loss.

Other symptoms include:

- Fatigue
- Low grade fever
- Joint pain
- Nausea and vomiting
- Mouth sores/ulcers, skin manifestations

The Crohn's & Colitis UK Symptom Checker was specifically developed to support people with gut symptoms, to provide insight into whether symptoms may be reflective of IBD, and to encourage seeking support from their GP.

There is no single approach to diagnosing IBD. It is based on a combination of clinical, biochemical, stool, endoscopic, cross-sectional imaging, and histological investigations.[2,3]

If IBD is suspected in primary care, faecal calprotectin (FC) will be measured to assess intestinal inflammation. Given its relatively high level of specificity and sensitivity, NICE recommends measuring FC levels to distinguish IBD from irritable bowel syndrome (IBS). This can ensure appropriate referral and earlier diagnosis of IBD, while minimising unnecessary investigations in those with IBS. If FC results are <100mcg/g, then IBS is likely (100-250mcg/g is borderline, >250mcg/g is high risk of IBD). Ideally, these tests would be undertaken prior to dietetic support. However, if you see a patient referred for IBS management that you suspect could have IBD, ask if they've had a FC test. If not, it is important to challenge the diagnosis and flag to the referring GP.

DELAYS IN DIAGNOSIS

In the last few decades, there has been significant advancements in the tools available to establish a diagnosis of IBD.

Despite this, delays in diagnosis remains a fundamental challenge.[4] In fact, the time to diagnosis hasn't really improved in the last 25 years.[5] In addition, there remains the challenge of potential misdiagnosis.

A study involving 19,555 IBD cases found that 1 in 4 cases reported GIS more than six months before a diagnosis, 1 in 10 cases reported GIS five years before a diagnosis, and some patients reported GIS up to ten years before a diagnosis. Those with a previous diagnosis of IBS or depression were less likely to receive timely specialist review.[6]

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Between 2019-2020, results from a UK-wide IBD Patient Survey (n=10,222 adults) found that 26% waited more than a year for a diagnosis, while 41% had visited Accident and Emergency (A&E) at least once before being diagnosed, with 12% visiting three or more times.[7]

Further studies have reflected similar findings with median diagnosis delays of 6 (2-23) months in CD and 3 (1-10) months in UC [8,9]

Reasons for delays in diagnosis

- Self-diagnosis (often IBS) and self-management (e.g. exclusion diets).
- Symptoms can be inconsistent, fluctuate over time and/or present gradually. When symptoms are less severe, it may be regarded as trivial and so appropriate tests are not performed.
- The overlap in symptoms with other common gastrointestinal disorders can result in a misdiagnosis, such as IBS.[10]
- Patients may present with non-specific symptoms such as tiredness/fatigue, weight loss, or joint pain.
- Several bottlenecks in the patient journey include lack of timely GP referrals, delays in endoscopy and specialist review.[11]

CONSEQUENCES OF DELAYS IN DIAGNOSIS

It is widely accepted that treating IBD at the earlier stages of disease and before large intestinal damage occurs is likely to lead to better clinical outcomes.[12] Pre-clinical damage is associated with immune dysregulation, gut microbiome alterations, tissue injury, which in many cases are irreversible.[12]

One recent systematic review and meta-analysis that pooled n=101 studies including 112,194 patients (59,359 with CD, 52,835 with UC) concluded that delayed diagnosis in CD was associated with an increased risk of stricturing, penetrating disease and intestinal surgery. In UC, delayed diagnosis was associated with an increased risk of colectomy.[13]

Additionally, a study of IBD patients with a delayed diagnosis found a delay as short as one week (between GP referral and specialist review) is significant in determining adverse outcomes (such as steroid and other rescue therapies, hospitalisations, surgery).[11,14]

Moreover, a systematic analysis found that adult CD patients have longer diagnostic delay compared with paediatric CD patients. Length of diagnostic delay was found to be predictive for CD-related complications in adult CD patients.[15]

Delays in IBD diagnosis highlights the need for education awareness in both primary and secondary care. The Crohn's & Colitis UK Early Diagnosis Campaign involves working with politicians and health leaders to support a national pathway across a range of health conditions for people presenting with lower gut symptoms, including Coeliac disease, IBS and IBD.

VISIT OUR CROHN'S & COLITIS UK CAMPAIGN

SUPPORT FOR DIETITIANS

Newly diagnosed[16]

IBD Toolkit[17]

Other resources[18]

The Dietitian Cafe podcast

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CONTINUED PROFESSIONAL DEVELOPMENT REFLECTION:

Prior to downloading a BDA accredited CPD certificate, we encourage you to reflect on this article and consider the following questions:

Q. What are the 3 key learning points you have taken away, after reading this article?

Q. How will the discussion points in this article change your approach to managing IBD patients in the future?

Q. Having read this article, are there any additional pieces of information, relating to IBD and Crohn's & Colitis UK, that you would like to find out? If so, how will you find this information?

Q. Consider opportunities to share what you have learnt in this article with your colleagues. What information would be particularly useful or relevant to them?