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Optimising the Inflammatory Bowel Disease Unit to Improve Quality of Care: Expert Recommendations

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Abstract

Introduction: The best care setting for patients with inflammatory bowel disease [IBD] may be in a dedicated unit. Whereas not all gastroenterology units have the same resources to develop dedicated IBD facilities and services, there are steps that can be taken by any unit to optimise patients' access to interdisciplinary expert care. A series of pragmatic recommendations relating to IBD unit optimisation have been developed through discussion among a large panel of international experts.
Methods: Suggested recommendations were extracted through systematic search of published evidence and structured requests for expert opinion. Physicians [n = 238] identified as IBD specialists by publications or clinical focus on IBD were invited for discussion and recommendation modification [Barcelona, Spain; 2014]. Final recommendations were voted on by the group. Participants also completed an online survey to evaluate their own experience related to IBD units.
Results: A total of 60% of attendees completed the survey, with 15% self-classifying their centre as a dedicated IBD unit. Only half of respondents indicated that they had a defined IBD treatment algorithm in place. Key recommendations included the need to develop a multidisciplinary team covering specifically-defined specialist expertise in IBD, to instil processes that facilitate cross-functional communication and to invest in shared care models of IBD management.
Conclusions: Optimising the setup of IBD units will require progressive leadership and willingness to challenge the status quo in order to provide better quality of care for our patients. IBD units are an important step towards harmonising care for IBD across Europe and for establishing standards for disease management programmes.

Keywords: Crohn's disease; decision making; delivery of healthcare; interdisciplinary communication; tertiary care centres; ulcerative colitis

1. Introduction

The long-term course of inflammatory bowel disease [IBD] is often characterised by symptomatic flare-ups and intermittent periods of remission. However, many patients develop a chronic, perpetual activity that can be only partially controlled and that leads to debilitating complications. IBD is typically managed by gastroenterologists, with input from colorectal surgeons as required. Other specialties involved in the care for complex cases include

rheumatology, dermatology, ophthalmology, nutrition specialists, gynaecology/urology and psychology. However, the multifaceted and complex nature of these diseases, together with the impact they have on patient quality of life, mean that they may best be managed in a dedicated IBD unit by a multidisciplinary team [MDT] with expertise in different aspects of the conditions.[1,2]

In addition, most therapies that have been approved to treat IBD induce a long-term [ie greater than 1 year] response in only 4050% of patients, with the percentage being even smaller if success is defined as achieving remission or disease control. The clinical studies that led to approval of such IBD therapies provide little or no evidence on how to optimise outcome through choice of drugs, dose modification or combination treatment. Large, multidisciplinary IBD units may offer greater expertise and aspects of quality control when considerable unmet medical needs have to be addressed.

Some excellent integrated models of care for IBD have been suggested.[3] However, not all gastroenterology centres can command the resources for large units. Nevertheless, there are steps that can be taken by any unit to create a clinical setting that optimises care for patients with IBD with regard to accurate diagnosis, proactive monitoring/disease management and timely introduction of appropriate treatment by expert healthcare professionals.

The purpose of this current initiative was to develop a series of pragmatic recommendations that could be adopted by any hospital or IBD unit to optimise quality of care.

2. Methods

In October 2013, a Steering Committee [EL, ID, SG, and SS] developed a preliminary series of recommendations relating to:

1. Role of the colorectal surgeon in an IBD unit
2. Establishment of an MDT
3. Structure of the IBD unit
4. Best practice procedures in an IBD unit
5. Best practice patient support in the IBD unit
6. Development and training of the MDT.

Three gastroenterology researchers [LM, CR, and Dörthe Schuldt] were nominated by the Steering Committee to conduct a structured evaluation of the published evidence on these recommendations. PubMed, EMBASE, and the Cochrane Library were searched using pre-defined search strings and limits, with additional hand-searching of references as required. In January 2014, preliminary recommendations and related scientific evidence were presented to 238 physicians who had been identified as IBD specialists by publications or clinical focus on IBD [invited from 41 countries] at a meeting in Barcelona, Spain. Participants were asked to complete an online survey before the meeting to evaluate their own experience in relation to dedicated IBD units, and then working groups were formed to discuss recommendations. Refinements were proposed as necessary according to published evidence and expert opinion. Meeting participants voted on their level of agreement with each refined recommendation using a scale of 1 to 9 [where 1 = strong disagreement and 9 = strong agreement]. If ≥ 75% of participants scored within the 7–9 range, then the recommendation was deemed to be agreed upon. If < 75% of participants scored within this range, the recommendation was debated and revised, and a second vote was taken. Each recommendation could be voted on a maximum of three times. Results of the online survey are presented here, followed by the findings of the literature review and agreed recommendations.

3. Results

3.1. Current status of IBD centres in selected European care settings

A total of 142/238 attendees [60%] completed the online survey before the meeting. Responses are shown in Table 1. Of particular note, only 15% of responding attendees were currently employed in a dedicated IBD unit [self-defined assessment], although the majority of attendees reported that they had relevant specialists working in their hospital/clinic and participants had been selected to represent gastroenterologists with particular clinical interest and expertise in IBD care. Educational resources and support for patients with IBD within hospitals/clinics were relatively low, with only 34% of respondents indicating that they had a patient support programme available. Whereas the majority of respondents reported that they had a treatment goal for each IBD patient, only half indicated that they had a defined IBD treatment algorithm in place.

3. 2. Recommendations for IBD unit optimisation

3.2.1. Role of the colorectal surgeon in an IBD unit

Surgery rates in IBD have decreased with improved therapy:[4] the 10-year cumulative risk of surgery remains around 15% in ulcerative colitis [UC] and 47% in Crohn's disease [CD].[5] The UK IBD Standards Group recommends that surgery be performed by an experienced colorectal surgeon who is a core member of the IBD team.[6] Other groups also recommend that IBD units include a surgeon or surgical team with IBD experience.[7] Indeed, several studies in populations undergoing colorectal surgery have shown that postoperative mortality and morbidity are decreased relative to the operating surgeon's volume of cases/experience[8,9,10,11] or subspecialty training.[11] In particular, patients requiring pouch / salvage pouch surgery or more complex CD procedures should have these operations carried out by specialists with appropriate training and experience.[6,7]

It is essential that there is close and structured integration of medical and surgical management to determine the right time for surgery and to prevent postoperative complications or recurrence.[1] This may take the form of a parallel or joint medical–surgical clinic in an IBD unit.[6,7] One prospective study in patients undergoing ileal pouch-anal anastomosis reported that joint patient care by a colorectal surgeon and an IBD-oriented gastroenterologist enhanced patient satisfaction compared with separate visits to gastroenterology or colorectal surgery clinics.[12]

Role of the colorectal surgeon in an IBD unit: recommendations:

3.2.1.1. The surgeon should have an interest in IBD and appropriate experience. *213/227 [94%] agreed*

3.2.1.2. There should be structured interaction between the gastroenterologist and the colorectal surgeon. *206/225 [92%] agreed*

3.2.1.3 There should be joint decision making before and after surgery, involving the gastroenterologist, colorectal surgeon and IBD patient. *213/226 [94%] agreed*

3.2.1.4. Pouch surgery should be performed in a regional centre capable of managing pouch-related complications. *207/227 [91%] agreed*

3.2.2. Establishment of the MDT

The complexity, heterogeneity, costs, patient impact and lifelong nature of IBD lends itself to being ideally managed by an MDT

Table 1. Online survey responses regarding work setting, resources and practice [*n* = 142; completed prior to meeting].

Question	Respondents, %
In what setting do you work for the majority of time?	
IBD unit	15%
Gastroenterology unit	27%
Gastroenterology/hepatology unit	42%
General hospital	16%
Which specialists currently work at your hospital/clinic?	
Colorectal surgeon	87%
IBD-specialist nurse	62%
Nutritionist	83%
Stoma specialist	62%
Psychologist/social services	66%
Imaging specialist to interpret scans/images	85%
Which resources do you have at your hospital?	
Endoscopy suite	97%
Imaging suite	88%
Practice guidelines for screening/diagnosis of IBD	72%
Therapeutic algorithms for treatment of IBD	75%
Practice guidelines for monitoring IBD	65%
IBD patient education	56%
IBD patient support programme	34%
Regular internal assessments/audits	37%
Do you assign a prognosis for every patient diagnosed with IBD	
Yes	23%
No	77%
Do you set a treatment goal for every patient with IBD	
Yes	88%
No	12%
Does your hospital have a defined treatment algorithm in place for the treatment of IBD?	
Yes	49%
No	51%

that includes a number of specialties and support services.[1,2] Several groups have provided recommendations on the composition of a core IBD team.[6,7] IBD specialist nurses provide patients with complication management, education, advocacy, and physical and emotional support.[13,14] Responsibilities may also include performing patient reviews, encouraging treatment adherence, running a telephone clinic, laboratory follow-ups, and prescription repeats.[13,15,16] Several studies have reported improvements in patient outcomes when a dedicated IBD nurse was involved in patient care, including fewer hospital admissions,[17,18,19] reduced length of hospital stay,[16,18] and temporary improvements in health-related quality of life.[20]

Malnutrition is common in patients with IBD, particularly those with CD. Nutritional care includes prevention or treatment of malnutrition and micronutrient deficiencies and, in children, promotion of optimal growth and development. Easy accessibility to a nutritionist or nutritional support team for comprehensive assessment and management has been recommended by several groups,[6,21] with the importance of specific knowledge of IBD highlighted in a survey of gastroenterologists.[15] Furthermore, specialists in stoma care have also been cited as important in the MDT.[6,7,21]

Endoscopy and cross-sectional imaging are essential for diagnostic confirmation of IBD and are also important monitoring tools over the course of the disease to document flare-ups, evaluate treatment efficacy, detect complications, identify postoperative recurrence, and perform colorectal cancer surveillance.[22,23] Close cooperation between the gastroenterologist and the endoscopist and/or radiologist is essential to ensure timely and accurate diagnosis and the most appropriate methods of ongoing monitoring. An international survey of gastroenterologists has recommended continuity of care by the same endoscopist.[21] Other recommendations are that endoscopic and radiology units are available in the same hospital as the IBD unit and that patients should be managed by endoscopists and radiologists with specific training or a special interest in IBD.[6,7] An IBD expert pathologist is important in the work-up of IBD patients, particularly for differential diagnosis and special situations inherent to therapy [such as the risk of cytomegalovirus infection reactivation].[24] Furthermore, the pathologist is fundamental to detecting precancerous lesions as part of a colorectal cancer surveillance programme.

Psychological distress, depression, and anxiety may trigger disease relapse; therefore, appropriate psychological interventions could improve treatment efficacy.[25] Furthermore, the input of a social worker with IBD experience may be useful in supporting patients and their caregivers with social services.[26]

However, it is not always possible to have all these personnel in one unit, owing to resourcing and financial constraints. IBD units should try to work with other departments in the same hospital or neighbouring centres to share services in a productive and cost-effective way. Importantly, however, the staff involved should have IBD experience so that the collaboration is effective and efficient. A higher level of professional satisfaction has been reported among health professionals who treat IBD patients exclusively relative to those who treat all patients with gastrointestinal disease.[27]

The UK IBD Standards Group recommends that scheduled weekly MDT meetings be held to discuss complex patients identified by the team, with formal recording of attendance and outcomes in the hospital notes.[6] This may involve networking with external healthcare professionals involved in the patient's care. This group also recommends that the MDT should agree on which member of the team will discuss any decisions with the patient. In addition, the majority of patients with IBD desire active involvement in the decision-making process of their disease management.[28,29,30] Indeed, the needs and views of the patient should be presented as part of the MDT discussion. It may even be appropriate to include the patient as part of the MDT meeting, although no literature was found to support this concept in IBD. Patient- and demand-directed care, which includes a direct telephone line for patients to a specialised nurse, appointments scheduled in accordance with expected needs, and emergency appointments available daily, has been shown to improve patient outcomes.[31]

Establishment of the MDT: recommendations:

3.2.2. In addition to a gastroenterologist and a colorectal surgeon, the MDT should include an IBD-specialist nurse, nutritionist, stoma specialist, radiologist, endoscopist, pathologist, psychologist and social worker. *178/224 [79%] agreed*

3.2.2.2. Each MDT member should have IBD experience. *181/225 [81%] agreed*

3.2.2.3. There should be structured interaction between the members of the MDT. *210/227 [93%] agreed*

3.2.2.4 The MDT should adopt a patient-centred approach that takes patient preferences and convenience into account. *195/223 [87%] agreed*

3.2.3. Structure of the IBD unit

There is some evidence in the literature that specialist IBD clinics may provide better care than the general gastroenterology clinics.[2] IBD represents a spectrum of challenging conditions that is best managed by a MDT that includes access to ancillary services with specific experience in treating patients with IBD.[1,7] Included in the ancillary services should be access to IBD-specific primary care, given that general practitioners typically see few IBD patients and may be uncomfortable with treating them.[15,32,33,34] Transition from paediatric to adult services needs to be carefully managed to allow an appropriate psychosocial development trajectory.[35,36] Fertility, pregnancy, and breastfeeding may all be affected by IBD, and patients may often be misinformed about fertility-related issues[37,38] thereby benefiting from appropriate access to obstetrics and gynaecology services. Furthermore, although there is a high prevalence of other immune-mediated inflammatory diseases [IMIDs] in patients with IBD,[39] many never consult an appropriate specialist[40] and potentially miss opportunities for accurate diagnosis and appropriate management.

Optimisation of any IBD unit needs to take into consideration the physical layout of the clinic. Several groups have outlined the ideal requirements for facilities [including toilets] and diagnostic and therapeutic equipment [including imaging facilities].[6,7,25]

There are conflicting data as to whether hospital volume influences mortality and morbidity rates,[8,10,11,41,42,43,44] although a number of studies suggest that there is a survival advantage in high-volume IBD admission centres, particularly in patients undergoing surgery. Several studies have defined high-volume IBD admission centres to include around 150 IBD-related hospitalisations each year.[43,44] A consensus conference sponsored by several German national societies involved in IBD used a nominal group process method to define 'high-volume' as a necessity for a certain threshold of IBD outpatients treated.[45]

Current treatment algorithms for IBD include use of biological therapy as standard in patients with aggressive disease or those refractory to conventional treatments. Clinical experience with these agents is important in ensuring optimal therapeutic effect and minimizing adverse events.[46,47] Furthermore, patients who do not respond to approved treatments should have the opportunity to participate in clinical trials.

Structure of the IBD unit: recommendations:

3.2.3.1 The unit should have an MDT specialising in IBD. *213/225 [95%] agreed*

3.2.3.2 Where appropriate, the unit should coordinate care with the following ancillary care providers: primary care practitioner; paediatric transition team; obstetrics/gynaecology specialist; and IMID specialists [eg rheumatologist, dermatologist]. Patients should be able to access emergency IBD care through the unit and intensive care facilities, if required. *175/219 [80%] agreed*

3.2.3.3 The unit should have dedicated space for all MDT activities. *189/224 [84%] agreed*

3.2.3.4 The unit should have adequate facilities for the specific needs of IBD patients, such as adequate toilets, washing rooms and preparation rooms [e.g. stoma care]. *191/222 [86%] agreed*

3.2.3.5 The unit should have an endoscopy suite, or structured access to a nearby endoscopy suite. *183/226 [81%] agreed*

3.2.3.6 The unit should have access to imaging [eg high-definition computed tomography or magnetic resonance imaging, or ultrasound where used]; a formalised discussion with a radiology specialist with IBD experience should be incorporated. *209/224 [81%] agreed*

3.2.3.7 The unit should manage a high volume of IBD patients. *176/221 [80%] agreed*

3.2.3.8 The unit should have experience in the administration of all approved drugs for IBD, including anti-tumour necrosis factor [TNF] therapy. *205/219 [94%] agreed* [Edited to add: anti-integrin therapy was commercially unavailable at the time the recommendations were developed.]

3.2.3.9 The unit should have access to clinical studies in IBD. *198/218 [91%] agreed*

3.2.4. Best practice procedures in an IBD unit

There is very little published evidence on the impact of documented guidelines on efficiency or clinical outcomes. Several groups have recently published recommendations on important process and outcome quality indicators or performance measures in IBD care.[22,48,49,50]

Best practice procedures in an IBD unit: recommendations:

3.2.4.1 The unit's practice guidelines should be clearly documented, and include: standardised referral data; diagnosis, and baseline assessment; entry points to care [referral from primary care, transition from paediatric to adult care, hospitalisation criteria, referral to surgery]; therapeutic algorithms; disease activity monitoring; and monitoring for side effects and adherence. *204/223 [92%] agreed*

3.2.4.2 Regular self-assessment of the unit should be conducted to see how quality of care and service may be improved. *212/224 [95%] agreed*

3.2.4.3 There should be systems in place to capture and respond to patient feedback on their experience and to give patients a voice in the continuous development of the IBD unit. *170/224 [76%] agreed*

3.2.4.4 The unit should keep thorough and accurate electronic patient records adapted to the IBD care unit. *182/226 [80%] agreed*

3.2.5. Best practice patient support in the IBD unit

Formal IBD patient education improves knowledge, perceived knowledge, and patient satisfaction.[51,2,53] In addition, several studies have shown that patient information recall can improve treatment adherence.[54,55] Telemedicine applications [such as teleconsulting and teleeducation] have been shown to improve treatment adherence, quality of life, and disease knowledge.[56] Structured or shared decision-making support for patients and caregivers may lead to more effective and efficient decision making, decreased psychosocial distress, and, ultimately, improved outcomes.[28,29,30,57] In addition, patient organisations may be useful in providing education, advocacy, and support to further improve the quality of life of patients with IBD:

Best practice support in an IBD unit: recommendations:

3.2.5.1 The unit should have a structured patient support programme that includes the following: appropriate patient education materials; patient education delivery and follow-up; and patient–MDT and patient–patient interaction opportunities [e.g. patient forum, patient 'open days']. *198/227 [87%] agreed*

3.2.5.2 Patient education and support should be structured to complement the clinical care provided. *209/224 [94%] agreed*

3.2.5.3 There should be shared decisionmmaking involving the gastroenterologist [and the MDT, if needed] and the IBD patient. *199/226 [88%] agreed*

3.2.5.4 Patients should be informed about recognised IBD patient organisations. *208/219 [95%] agreed*

3.2.6. Development and training of the MDT

Guideline adherence is not always optimal among IBD-treating physicians,[15,58] possibly due to lack of knowledge, belief that the guidelines are already incorporated into practice or lack of relevance. Several consensus documents on IBD care advocate that MDTs receive specific training on guidelines.[6,7]

Development and training of the MDT: recommendations:

3.2.6.1 The MDT should receive training on the unit's agreed IBD guidelines. *207/220 [94%] agreed*

3.2.6.2 The latest local and regional IBD guidelines should be incorporated into the unit's practice guidelines, and these updates communicated to the MDT in a structured way. *212/221 [96%] agreed*

3.2.6.3 Representative members of the MDT should be encouraged to attend IBD-related meetings regularly. *189/213 [89%] agreed*

4. Discussion

As shown by the survey completed by the working group, specific IBD units are relatively uncommon in Europe and not all patients have predefined access to complementary specialists outside gastroenterology. Defined IBD treatment algorithms or structured processes to derive therapeutic decisions are not in place in more than half of care settings, and structured support for IBD patients is only established in a few instances. This is particularly relevant, given that the respondents represented IBD specialists from centres with specific interest and reputation in IBD care. On a broad scale, it is likely that specialist IBD units and associated standards for IBD of care are vastly lacking throughout Europe.

It is clear that there is room for improvement in the quality of care that we offer to our patients with IBD. We believe that this can be achieved with well-considered and intentional changes to our existing gastroenterology departments to create optimised IBD-specific units staffed by an IBD-focused MDT.

Although a substantial body of work has recently been published regarding quality indicators in IBD,[22,48,49,50] there is currently a lack of evidence to guide optimisation of dedicated IBD units, particularly with respect to the composition of the MDT, required physical resources, training, documentation, and patient support.

The recommendations presented here are largely based on expert experience and pragmatism, and supported where possible by published evidence. Key points include the need develop an MDT with specific expertise in IBD, to instil processes that facilitate communication between different team members and patients, to provide clear documentation, and to invest in shared-care models of IBD management. It should also be remembered that these recommendations have been generated by a group of physicians and represent medical priorities that may be different from those of allied healthcare professionals or IBD patients. It is essential to consider the perspectives of these groups when engaging in strategies to optimise IBD centres.

In chronic diseases that lead to destruction of target organs, long-term outcomes can be vastly improved by disease management programmes. For example, care programmes for diabetes mellitus or arterial hypertension benefit from multidisciplinary therapeutic settings, therapeutic choice, and a defined disease management with ongoing diagnostic investigations and therapeutic adjustments.[59,60] It appears likely that IBD could also benefit from management programmes that include a 'treat-to-target' commitment. It will be instrumental to support this strategy with IBD centres that have a critical size and that meet the standards discussed in this article.

We recognise that there may be large discrepancies between the recommendations presented here and the reality of many hospitals and outpatient centres treating patients with IBD. However, although some centres may not have the resources to develop ideal settings, this need not be a barrier to taking small steps to optimise care in dedicated IBD units. Such change will require progressive leadership and willingness to challenge the status quo in order to provide better quality of care for our IBD patients.

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Conflicts of Interest

EL has: received research grants from AbbVie, AstraZeneca, and Merck; received speaker fees from AbbVie, AstraZeneca, Chiesi, Dr Falk Pharmaceuticals, Ferring, Menarini, Merck, Merck Sharp & Dohme, Nycomed, and UCB Pharma; been involved in advisory boards for AbbVie, Ferring, Merck Sharp & Dohme, Millennium, Mitsubishi Pharma, Takeda and UCB Pharma; acted as a consultant for AbbVie.

ID has: received research grants from AbbVie; received speaker fees from AbbVie, Dr Falk Pharmaceuticals, Ferring, Janssen, and Merck Sharp & Dohme; been involved in advisory boards for AbbVie, Genentech, Janssen, Pfizer and Takeda.

SG has: received research support from AbbVie and Pentax; received speaker fees from AbbVie and Janssen; and been on steering committees for AbbVie, Bristol-Myers Squibb, Janssen, Novo Nordisk, Pfizer, and Receptos.

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