



REVIEW ARTICLE

Improving quality of care in inflammatory bowel disease: What changes can be made today? ☆



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Abstract

Background and aims: There are a number of gaps in our current quality of care for patients with inflammatory bowel diseases. This review proposes changes that could be made now to improve inflammatory bowel disease care.

Methods: Evidence from the literature and clinical experience are presented that illustrate best practice for improving current quality of care of patients with inflammatory bowel diseases.

Results: Best care for inflammatory bowel disease patients will involve services provided by a multidisciplinary team, ideally delivered at a centre of excellence and founded on current guidelines. Dedicated telephone support lines, virtual clinics and networking may also provide models through which to deliver high-quality, expert integrated patient care. Improved physician–patient collaboration may improve treatment adherence, producing tangible improvements in disease outcomes, and may also allow patients to better understand the benefits and risks of a disease management plan. Coaching programmes and tools that improve patient self-management and empowerment are likely to be supported by payers if these can be shown to reduce long-term disability.

Abbreviations: CRP, C-reactive protein; HCP, healthcare professional; IMID, immune-mediated inflammatory diseases; MDT, multidisciplinary team.

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Conclusions: Halting disease progression before there is widespread bowel damage and disability are ideal goals of inflammatory bowel disease management. Improving patient–physician communication and supporting patients in their understanding of the evidence base are vital for ensuring patient commitment and involvement in the long-term management of their condition. Furthermore, there is a need to create more centres of excellence and to develop inflammatory bowel disease networks to ensure a consistent level of care across different settings.

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1. An introductory overview: what can we do better?

Inflammatory bowel diseases (IBDs) are emerging as a worldwide epidemic, with prevalence of around 1% in North America and some European countries, and a rapid increase in incidence reported in Asia, China and Australasia.¹ A number of recent reports and publications point to the burden that this rising tide of IBD is imposing on patients, healthcare services and society. For example, a comprehensive and large-scale study in Denmark comparing ulcerative colitis (UC) and Crohn's disease (CD) patients with matched controls has shown that a diagnosis of IBD increases both immediate- and long-term risk of mortality.² Furthermore, patients with IBD are more likely to be in receipt of disability allowances than age-matched individuals from the general population,³ reflecting the impact of an IBD diagnosis on health-related quality of life and productivity.

1.1. Earlier diagnosis, earlier intervention and better adherence to guidelines

The IMPACT patient survey, conducted in 27 European countries and sampling responses from almost 5000 IBD patients (63% CD, 33% UC), highlights a number of gaps in current clinical care.⁴ Overall, 18% of IBD patients reported that they waited over for 5 years before receiving a diagnosis, and 67% needed emergency care before receiving a diagnosis. Moreover, 53% reported they felt unable to tell their doctor something important at a consultation. Other evidence that suggests that there is room for improvement in the current care of patients with IBD comes from a recent

survey of IBD patients in France.⁵ This questionnaire-based study found that, contrary to current guideline recommendations, only around 30% of patients with long-standing extensive colitis received a screening colonoscopy. Furthermore, a US physician survey reported that 29% of physicians were unaware of guidelines recommending venous thromboembolism prophylaxis in hospitalised IBD patients and that only 35% would provide pharmacological prophylaxis to hospitalised patients with severe UC.⁶ There is also evidence from population-based studies that many patients are still treated late in the course of their disease, even with current-day treatment algorithms founded on earlier use of immunosuppressants and biological therapy.⁷ One of the issues that complicate quality of care is the plethora of guidelines available from a number of professional societies, covering a range of specific scenarios. At least some of these may be rapidly outdated and may be difficult to locate or follow, particularly by non-IBD specialists.

1.2. Preventing long-term disease progression

There is a need for wider appreciation of the progressive nature of IBD and the importance of early diagnosis and intervention at earlier stages of disease, ideally before disease progression occurs.^{8,9} In CD, there is progressive digestive damage in addition to the characteristic episodes of inflammatory activity, with a growing body of evidence showing that this condition needs to be viewed not simply as series of intermittent flares but as a disease with a continuous pathology⁹ (Fig. 1). There are also emerging data to suggest that mucosal healing in CD and UC patients is associated with a reduction in the need for subsequent surgical resection over the following decade.¹⁰ The role of

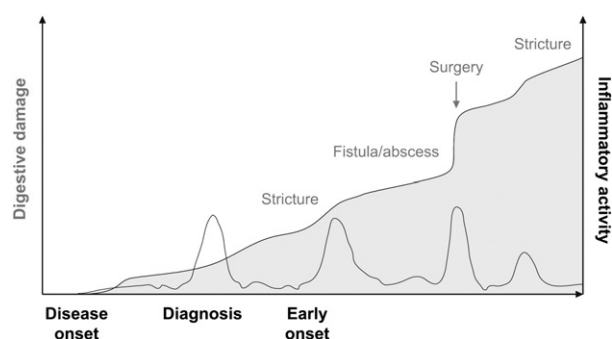


Figure 1 Progression of digestive damage and inflammatory activity in a theoretical patient with CD. This graphical representation shows that each symptom flare produces cumulative damage to the digestive tract. The role of early treatment in delaying or preventing structural bowel damage and associated disability is an important area of current research. Figure reproduced and adapted from Pariente et al,⁴² with permission from Lippincott Williams & Wilkins, Inc. © 2011.

early intense therapy in preventing disease complications and disability is therefore an important area of research.

There is some evidence that patients treated with tumour necrosis factor (TNF) antagonists within the first two years after CD diagnosis will achieve better remission rates than those in whom treatment is started between two and five years or more than five years after diagnosis.¹¹ Criteria that should prompt early and intensive therapy include extensive CD, severe upper tract disease, severe rectal disease, complicated disease behaviour at diagnosis, complex perianal disease, severe endoscopic lesions and failure to thrive (in paediatric patients). There is hope that the increasing study and use of prognostic and predictive biomarkers may hold a key to improving and tightening patient monitoring, management and disease control. For example, C-reactive protein (CRP) levels appear to be predictive of level of response to biologic therapy.¹² There are a number of on-going clinical trials, including the CALM (NCT01235689) and REACT-2 (NCT01698307) studies, that hope to determine the value of early and tight disease control on clinical outcomes in CD. For patients on treatment, there is also a need for consistent and agreed approaches to managing loss of response, founded on disease and drug monitoring protocols and algorithms that ensure appropriate treatment intensification or treatment switching, according to patient needs.^{13–16}

2. What do we do well and what difference has it made?

The best care for patients with IBD appears to come from services provided by a multidisciplinary team (MDT) (Table 1), ideally delivered at an IBD centre of excellence and founded on current consensus.^{17–19} High-volume IBD centres have been shown to provide better surgical outcomes than non-specialist centres.²⁰ Care delivered by a MDT at an IBD centre of excellence offers an effective model for long-term care of patients with IBD and reflects

Table 1 Suggested composition of an inflammatory bowel disease multidisciplinary team.

Core team	Gastroenterologists IBD nurse specialists Surgeons Radiologists Pathologists Specialist pharmacists
Complementary team	Dieticians Psychologists Social workers Paediatricians Rheumatologists Dermatologists Ophthalmologists Infectious disease specialists

the need to be adaptable and responsive to patients with changeable and progressive disease.

At St Mark's Hospital in London, the IBD team comprises 15 gastroenterologists, 10 surgeons and five specialist nursing teams (including an IBD nursing team, stoma and pouch nurses, nutrition nurses and an endoscopy nursing team), as well as pharmacy, radiology, paediatrics and clinical research. Weekly IBD MDT meetings take place, including a main IBD MDT meeting, a virtual biologics meeting, a dysplasia/polyp meeting, a psychosocial meeting and an IBD executive meeting (for the purposes of service planning). The IBD MDT meeting allows for MDT consideration of complex patients and/or diagnostic dilemmas to create a clear care plan. The virtual biologics meeting is designed to ensure a consistent approach to treatment and monitoring for patients receiving anti-TNF therapy. The patient's general practitioner and the relevant funding body are also provided with an update on the patient's progress to ensure that treatment continues without interruption. Meetings are documented to allow appropriate correspondence regarding clinical decisions to general practitioners and patients. Patients with chronic diseases such as IBD need to learn self-management while having a supportive network and access to prompt care and advice when unwell. The IBD specialist nurse plays a key liaison role with the patient, acting as their advocate at MDT meetings and ensuring that the focus is on managing IBD in the context of the patient's life, rather than just in terms of disease activity. Specialist nurses are a key point of access for patients for education and information and are also a means for patients to share and discuss the impact of disease on everyday life, specific symptom difficulties and the complexities of living with a somewhat "invisible" disease.²¹ What IBD patients want from nurses is to be listened to, and to be given information, honest dialogue about their disease, a relationship or connection and hope of a more normal life. A continuing focus of nurses is to determine a patient's ability to manage their illness in the context of their life, by listening to and supporting patients and providing care and information according to individual patient needs. Providing a dedicated IBD telephone line for patients is an example of a tool that allows swift appropriate access to advice and care,

particularly during periods of ill-health.²² Virtual clinics and networking may also provide models through which to deliver high-quality, expert integrated patient care in IBD.²³

IBD centres of excellence may not be the norm for IBD care in every jurisdiction. For example, very few countries allocate specialist nursing staff as permanent personnel in IBD units. Nevertheless, this kind of model can provide us with opportunity to evaluate best-practice strategies and tailor these to other contexts as resources allow.

3. Fostering physician–patient collaboration

Fostering collaboration between the patient and their healthcare team is particularly important in terms of optimising treatment adherence. Patients need to accept the need for a therapeutic intervention, then adhere and persist with that intervention, in order to succeed in reaching the goals of remission, prevention of damage and prevention of physical disability. The motivation to start and continue on a medication is known to be influenced by how patients judge their personal need for medication relative to their concerns about potential adverse events.²⁴ A cross-sectional survey of 1871 members of the National Association for Colitis and CD in the UK highlighted that acceptance of the need for a treatment is the primary challenge to adhering to maintenance treatment.²⁵ The literature provides a number of reports showing that patients with IBD struggle to adhere to their prescribed medication over time. For example, while more than 90% of CD patients reported good adherence to thiopurine therapy at 3 months,²⁶ another study found that only 26% of patients reported adhering to their prescribed therapy after 4 years.²⁷ A systematic review of 13 observational studies of adherence to anti-TNF therapy in IBD found a pooled treatment adherence rate of 83% (37–96%) with lower adherence rates in UC than in CD.²⁸ Often poor adherence is unintentional (such as forgetting to take medication or taking medication incorrectly) and is therefore preventable. Sometimes, however, adherence is intentional with strong predictors of intentional non-adherence which include concerns about treatment side effects, beliefs about illness, the perceived need for treatment and perceptions regarding treatment efficacy (Table 2).²⁹ Even intentional non-adherence can be reduced by addressing patient misconceptions or beliefs about the disease and its

treatments. In the UK, the National Institute for Health and Clinical Excellence guidelines on medicine adherence stress that patient involvement is key to improving adherence (Fig. 2).³⁰ Furthermore, a meta-analysis has shown that healthcare professional (HCP) communication significantly and positively correlates with improved patient adherence.³¹ Physician training in communication skills increased adherence significantly and pre-treatment elicitation of concerns predicted subsequent adherence. Programmes that include motivational interviewing (described by Miller and Rollnick³² as “...a collaborative, conversation style for strengthening a person's own motivation and commitment to change” [p. 12]) could help encourage improved understanding of disease and treatment, better appreciation of risks versus benefits and ultimately improved adherence to therapy and monitoring. Cost of treatment in relation to income may also be a factor impacting adherence to treatment,²⁹ although little investigation has been performed around this determinant in the IBD context. Addressing this barrier to treatment requires the participation of health system engineers, payers, patient groups and, of course, the IBD treatment industry.

More research is needed into why patients with immune-mediated inflammatory diseases (IMIDs) have treatment adherence difficulties. The ALIGN study (UKRN ID: 12782) is a multinational cross-sectional study to determine patient-specific and general beliefs in patients with IMIDs; 7300 patients with one of six diagnoses will be assessed in 35 countries. ALIGN will use a validated questionnaire to collect data on beliefs and concerns that will be correlated with disease and treatment history.

4. Communicating benefit/risk to patients

Patients who understand the benefits and risks of a disease management plan are likely to be more accepting of it and willing to share in and follow their treatment and monitoring schedules. In addition, a study in patients with CD has shown that patients are willing to trade risks incurred by therapies for benefits associated with their use.³³ Patients completed choice-format conjoint trade-off tasks involving hypothetical treatments with varying efficacy and risk levels. Benefits and risks were described in terms of daily symptoms and activity limitations, serious complications of CD, time between flare-ups, exposure to steroids and risk of serious adverse events known to be associated with CD treatment (for example, progressive multifocal leukoencephalopathy, serious infections and lymphoma). Patients were willing to accept elevated risks in exchange for clinical efficacy, interestingly at an order of magnitude greater than those known to be associated with IBD drug therapy. However, communicating risks and benefits to patients is not necessarily easy as one cannot assume that the patient has an ability to understand even simple statistical terms. In addition, the way that risks and benefits are presented can be misinterpreted by the patient. For example, in a study at a US tertiary care centre, patients asked to choose between two equally efficacious drugs – drug R (said to decrease relative risk of death by 80%) and drug A (said to prevent eight deaths in 100 people) – were more likely to choose drug R.³⁴ In addition, “denominator neglect” can lead to

Table 2 Top reasons for medication non-fulfilment and non-persistence in patients with chronic disease in the USA.²⁹ Survey participants were selected from the Harris Interactive Chronic Illness Panel. Of the 19,794 respondents eligible for the non-persistence analysis, 2756 reported non-persistence for at least one prescription in the previous year and were included in the analysis.

Financial hardship
Fear or experience of side effects
Generic concerns about medications
Lack of perceived need for medication
Change in health insurance or drug benefits
Did not believe that condition was life-threatening

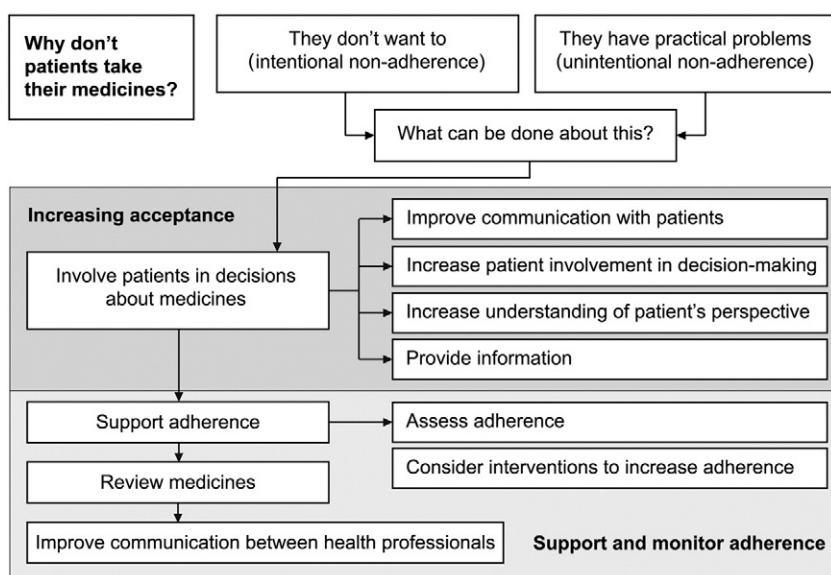


Figure 2 Summary of the UK National Institute for Health and Clinical Excellence care pathway for supporting treatment adherence in patients with chronic diseases.³⁰ The recommendations highlight the importance of patient involvement in making decisions about medicines as a key to increasing acceptance.

over- or under-estimation of benefit or risk.³⁵ Therefore, it is important to present patients with data in a consistent statistical format to allow them to make valid comparisons. This means using absolute rather than relative risk, using the same denominator across different scenarios, explaining percentages as fractions and avoiding inaccurate terms.³⁶ Icon arrays can be very helpful in illustrating benefit and risk data (Fig. 3) and graphical depiction may be helpful depending on a patient's graph literacy skills.^{35–37} The future of communicating risks and benefits may lie in system dynamics modelling where data are collected on the disease course and its alteration by different treatments, and then personalised to the patient based on a number of demographic and phenotypic inputs and presented in an easily understood graphical format.³⁶

5. Working within the healthcare system to improve care

Payers have a vested interest in ensuring that patients with IBD receive optimal early care with a goal of reducing long-term disease progression and disability. Nevertheless, earlier care may have a more immediate cost associated with it. State healthcare providers face the challenge of achieving the best health outcomes from available funding across whole populations and may, therefore, be more concerned with treatment than prevention. Healthcare funds in the European Union typically operate within the Association Internationale de la Mutualité (AIM: a 46 member mutual comprising 25 countries and reflecting 85% of

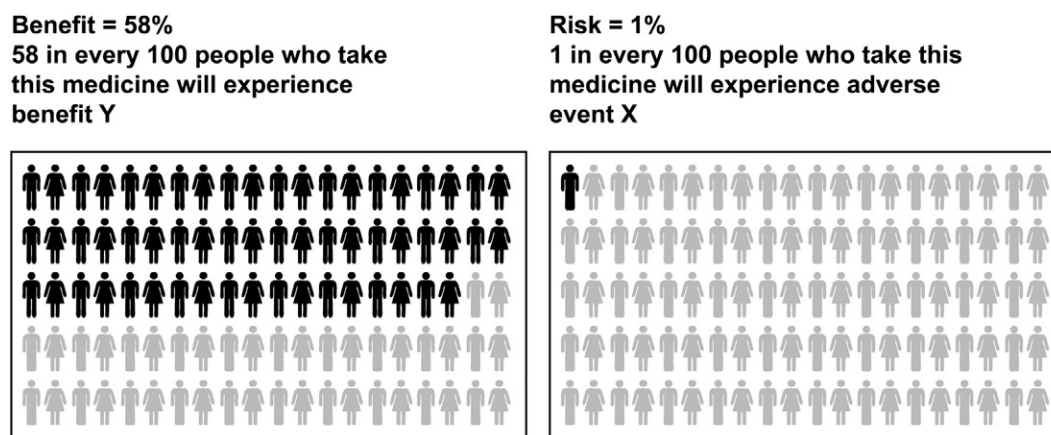


Figure 3 An example of a simple icon array to illustrate and explain treatment benefit and risk data to patients. Arrays with 1000 or 10,000 patients can be used to indicate percentages <1%.

members of the EU) or the European Social Insurance Platform (ESIP). These mutuals in health insurance work together in their approach to chronic clinical conditions by seeking the most effective means of reimbursement of care costs. Furthermore, they are supportive of new models of care that recognise that the societal costs of chronic diseases are impacted by measures that target prevention, individualise care, reduce hospitalisations and limit disability. AIM strives towards integrated customised care – that is, efficient care that integrates primary and secondary care services, considers service packages and medical and social care, and is customised to focus on lifetime periods and risk management as well as on individual case management needs. Integrated services are supportive of early disease diagnosis and the re-use of data to help predictive modelling and enrolment of patients into care schemes. Health payers are also supportive of coaching programmes and tools that improve patient self-management and empowerment (such as electronic personal health records). Such measures may be used in pay-for-performance programmes. Improvement in the care of patients with chronic disease is possible by creating both political and healthcare service structures that are willing, ready and able to deliver new services offering earlier diagnosis and treatment. Payers are important stakeholders and only by integrating patient and payer perspectives can the burden of chronic diseases be efficiently and effectively tackled.

6. The future — what needs to be done

In the future, developments in disease phenotyping and genotyping may help inform earlier intervention. A plethora of new and emerging therapeutic agents and interventions affected through differing mechanisms of action should also help improve future management of IBD.³⁸ Improving patient–physician communication and supporting patients in their understanding of the evidence base are also important for ensuring patient commitment and involvement in the long-term management of their condition.^{39–41} There is also a desire to create more IBD centres of excellence and to develop IBD networks to ensure a consistent level of care across different settings – working alone is no longer acceptable. Finally, improved communication may hold the key to empowering and allowing patients to actively participate in disease management.

However, as with pharmacological interventions, quality interventions also need evaluated on evidence. While structure and process measures, such as those described in this paper, improve the care that we give to our patients with IBD, the tangible impact of these strategies on disease outcomes has yet to be clearly established. Robust reporting systems need to be implemented so that we can evaluate whether changes in structure and process definitively drive better meaningful clinical outcomes. Furthermore, the cost-effectiveness of such measures needs to be carefully considered, particularly in the current economic climate, which is characterised by the disintegration of social security systems due to austerity measures. It is likely that quality of care and accessibility to treatment will continue to be a primary focus for professional and patient associations

across the world as we strive to improve outcomes for our patients with IBD.

Conflict of interest

Dr Panés has received speaker fees from AbbVie, MSD, Shire Pharmaceuticals and UCB; acted as a scientific consultant for AbbVie, Actelion, Boehringer Ingelheim, Bristol-Myers Squibb, Ferring, Genentech, Janssen, MSD, Novartis, Nutrition Science Partners, Pfizer, Shire Pharmaceuticals, Tygenics and UCB Pharma; and received research grants from AbbVie and MSD.

Ms O'Connor has received speaker fees from AbbVie, MSD and Warner Chilcott. She has also received consultancy fees from AbbVie, MSD and Vifor Pharma.

Professor Peyrin-Biroulet has received consulting and/or lecture fees from AbbVie, Boehringer Ingelheim, Bristol-Myers Squibb, Ferring, Genentech, Hospira, Janssen, Merck, Mitsubishi, Norgine, Pharmacosmos, Pilege, Shire Pharmaceuticals, Takeda, Therakos, Tillotts Pharma, UCB Pharma and Vifor Pharma.

Dr Irving has received speaker fees from AbbVie, MSD, Warner Chilcott, Ferring and Shire Pharmaceuticals. He has received consultancy fees from AbbVie, Pharmacosmos, Genentech, MSD, Shire Pharmaceuticals and Warner Chilcott.

Dr Petersson is an employee of and shareholder in AbbVie.

Professor Colombel has received consulting and/or lecture fees from AbbVie, ActoGeniX, Albireo Pharma, Amgen, AstraZeneca, Bayer AG, Biogen Idec, Boehringer Ingelheim GmbH, Bristol-Myers Squibb, Cellerix, Centocor, Chemo Centryx, Cosmo Technologies, Danone Research, Elan Pharmaceuticals, Genentech, Giuliani SpA, Given Imaging, GlaxoSmithKline, Hutchison MediPharma, MSD, Millennium Pharmaceuticals Inc. (now Takeda), Neovacs, Ocera Therapeutics Inc., Otsuka America Pharmaceutical, Pfizer, Shire Pharmaceuticals, Prometheus Laboratories, Sanofi-Aventis, Schering-Plough, Synta Pharmaceuticals Corp., Teva, Therakos, Tillotts Pharma, UCB Pharma and Wyeth, and has stock ownership in Intestinal Biotech Development, Lille, France.

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Dr Jan van Emelen provided the original content for his presentation at the meeting, which was used in the development of the manuscript.

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