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Gastroenterology in Primary Care
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Primary Care Society for Gastroenterology

Editorial

This may well be the first issue seen by some of our new members, so may I extend a warm welcome from us all to those who have joined recently. As with all societies, the PCSG depends heavily on the support and participation of its members so please get involved either by offering articles, attending meetings or interacting with our website www.pcsg.org.uk.

There is still a lack of clarity about many parts of the new NHS post White Paper but one thing is clear and that is what many consortia will need is authoritative advice on all aspects of the interface between primary and secondary care. Gastroenterology is an important aspect of this so we I would urge you to get involved with your local consortia and, at least, ask questions as to how gastroenterology is viewed in their plans. The ongoing problem of total lack of gastroenterology in the Qualities and Outcome Framework has given the wrong impression that it is less important. This is despite the large morbidity and mortality seen in gastroenterology especially in liver disease and GI cancer. The stronger the PCSG becomes, the stronger our voice will be in our role of championing primary care gastroenterology. So, please, inform your colleagues as to what and whom we represent and, better still, encourage them to join the PCSG.

In this issue, we have mostly centred on IBD. The range of illnesses comprising the term IBD (predominantly Ulcerative Colitis and Crohns) impact on far more people than we often think,with nearly 250,000 people in the UK affected by Crohns and Ulcerative Colitis alone, affecting 400 out of every 100,000 people.

No illness ever comes at the right time but IBD often starts in the teenage years, a time of flux with all the stresses of the move to adulthood and the start of IBD at such a time can often cause tremendous stress. IBD is also a chronic condition requiring long term support and medication.

In this issue, Tanay Sheth will be highlighting an important advance in speeding up the diagnosis of IBD using faecal calprotectin. We also look at the difficulties in diagnosis with two case histories presented by John Galloway. Rod Mitchell has contributed a short piece on the valuable work done by CICRA (Crohn's in Childhood Research) in raising awareness that IBD is not just a disease affecting adults but one that cause great difficulties for far more young people than most people realise.

Chris Healey and I have collaborated on an article on the common practice of drug switching in 5-ASA therapy. We both remain concerned that, although based on anecdotal evidence, many patients with IBD on 5 -ASAs are having flare ups due to ill thought out drug switches, a practice that may become more prevalent in our straightened times.

Finally, although not related to IBD, I have included an article from Norma McGough who is Head of Diet and Health at Coeliac UK. As most of you will be aware, many PCTs are restricting many prescription gluten free products but doing very little to rethink how services to coeliac patients can be improved. Norma shows how Coeliac UK is meeting the challenges of the new NHS world with new ways of thinking in terms of service redesign.

My thanks to all our contributors for their articles and don't forget to check for details on the website of our upcoming meetings at the BSG and our endoscopy day in June.

John O'Malley

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Faecal Calprotectin in the Diagnosis of Inflammatory Bowel Disease

Dr Tanay Sheth, GPSI Gastroenterology

Introduction

Patients presenting to their General Practitioners with persistent or recurrent abdominal pain and diarrhoea can present a difficult diagnostic problem. How do we differentiate the few who may have organic disease including inflammatory bowel disease (IBD) and who need urgent referral to secondary care for investigation and treatment, from the many who probably have irritable bowel syndrome (IBS) and who can be reassured and treated in primary care? This is particularly the case in younger patients without rectal bleeding, weight loss, family history of IBD, abdominal mass, anaemia, or high erythrocyte sedimentation rate (ESR) and C-reactive protein (CRP).

As a result, many patients with IBS are referred for lower gastrointestinal endoscopy (colonoscopy or sigmoidoscopy), which is expensive, invasive, involves inconvenient bowel preparation, and can be very uncomfortable for those with visceral hypersensitivity. Further, some patients with IBD presenting with IBS-like features may experience a delay in their diagnosis.

What if we had a simple and cheap screening test that could help us reliably differentiate between these two groups? This would have clear benefits for patients, clinicians and commissioners. We could reduce the number of unnecessary endoscopies performed for patients identified as low risk, while justifying urgent investigation for those at high risk of having IBD. Testing for faecal calprotectin may hold the promise of such a test.

Faecal calprotectin

Calprotectin is a low molecular weight 36kDa calcium and zinc binding protein that is abundant in the cytosol of neutrophils, and to a lesser extent that of monocytes and macrophages. It is released in inflamed tissues as part of the primary immune response and it has been shown to have anti-microbial and anti-proliferative properties. Calprotectin released in inflamed gut is resistant to enzymatic degradation and remains stable in faeces for up to one week at ambient temperatures. This allows for convenient stool sample collection.

Three assay modalities are currently available for faecal calprotectin. It can be measured in the laboratory by standard quantitative enzyme-linked immunosorbent assay (ELISA), in the clinic using a quantitative rapid test kit, or at home by the patient using a semi-quantitative/qualitative lateral flow chromatographic immunoassay (akin to a urinary pregnancy test).

Evidence for use as a diagnostic test

The performance of faecal calprotectin as a diagnostic test for IBD has been evaluated numerous times over the past decade.

In early 2010, the Department of Health's Centre for Evidence-based Purchasing (CEP) published comprehensive reviews on faecal calprotectin [1, 2]. The summary of the CEP's verdict was that faecal calprotectin testing performed better than other diagnostic tests including ESR and CRP, and it offered the NHS potential for substantial cost savings by reducing the need for secondary care referral.

In mid-2010, van Rheenen et al published a meta-analysis of diagnostic accuracy studies in the British Medical Journal [3]. This looked at measurement of faecal calprotectin by ELISA (index test) compared to ileocolonoscopy (reference standard) in 6 prospective studies in adults and 7 in children. The meta-analysis found faecal calprotectin testing had a pooled sensitivity of 93% (95% confidence interval 85-97%) and pooled specificity of 96% (95% confidence interval 79-99%) in adults. The performance in children was lower, with a pooled sensitivity of 92% (95% confidence interval 84-96%) but a pooled specificity of 76% (95% confidence interval 62-86%). Reasons for the lower specificity (i.e. higher false positive rate) in children were discussed in the paper and the accompanying editorial [4], and include possible case-mix issues, undetected small bowel disease, and infectious diarrhoea which may have resolved between testing and endoscopy.

Implications

There is general agreement on the increased use of faecal calprotectin in the diagnosis and monitoring of IBD in secondary care, but how applicable are the findings of the meta-analysis to primary care? The authors of the meta-analysis and the editorial express reservation. We do not yet have any good evidence of how the test performs in primary care. All the studies included in the meta-analysis were carried out in secondary and tertiary care, where there was an average IBD prevalence of 32%. The prevalence of IBD in the patients who present to us will be substantially lower (a figure of 5% is used as an

example in the meta-analysis). Lower prevalence will reduce the positive predictive value but increase the negative predictive value, provided likelihood ratios remained constant. It is possible that patient characteristics may be different between the two populations. There is also little comparative data on the performance of the various faecal calprotectin assays available.

Nevertheless, faecal calprotectin testing has already been shortlisted for implementation in primary care pilots across a number of Strategic Health Authority regions as part of the Department of Health's Innovative Technology Adoption Procurement Programme (Walton K of Alpha Laboratories, personal communication, 1 February 2011).

If primary care studies confirm good test performance (especially excellent negative predictive values that would help to 'rule out' IBD), faecal calprotectin will be a major step forward in the way we investigate patients presenting to us with lower gastrointestinal symptoms.

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Dr Tanay Sheth, GPSI Gastroenterology

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IBD Case histories

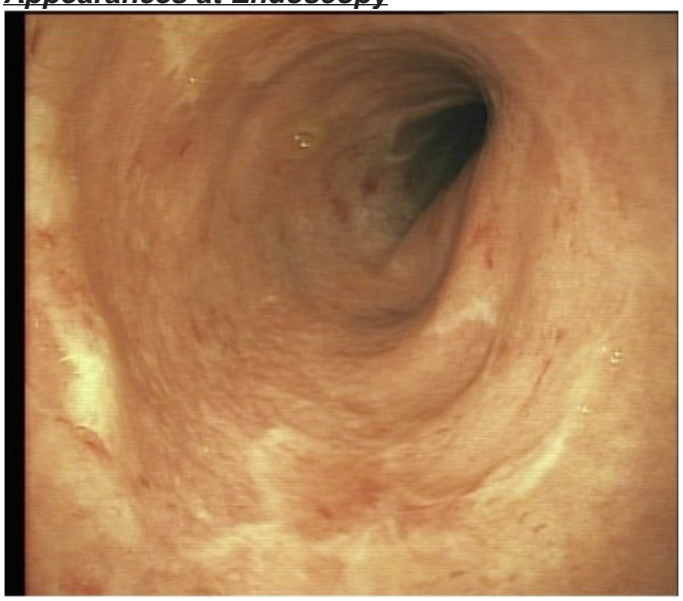
This is,hopefully, the beginning of a series of articles where members can share case histories that they think raise issues that should be shown to the wider membership.

Our inaugural article is written by John Galloway who continues to be a foremost figure in primary care based endoscopy.

IBD Case History 1

In May 2007 a 24 year old male lecturer presented with a 3 week history of passing loose stools with a small amount of mixed blood. There were no nocturnal symptoms and his joints felt stiff in the mornings. He gave a family history of his mother suffering with erythema nodosum at the age of 20 and a maternal aunt died from colorectal cancer at the age of 47.
Initial investigations showed a normal stool culture and normal FBC and thyroid function. His ESR was 10 mm and C reactive protein 5.
A differential diagnosis of inflammatory or irritable bowel disease was made and he was referred for a flexible sigmoidoscopy.
The flexible sigmoidoscopy was performed 3 weeks later and by this time he reported that his bowels were open up to 10 times per day and he had lost about a stone in weight since the beginning of the illness. The flexible sigmoidoscopy to the splenic flexure showed mild to moderate inflammation to the extent of the examination and a clinical diagnosis of ulcerative colitis was made. He was started on prednisolone at 40 mg per day.

Appearances at Endoscopy



Histology was reported as showing changes of acute inflammatory bowel disease, the features favouring ulcerative colitis rather than Crohn's disease.
He was reviewed 7 days after starting the prednisolone and he reported that the frequency of bowel action was the same but the stools were more formed. The joint stiffness and arthralgia remained the same. Mesalazine was added into the regime at a dose of 3 g orally per day.
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He was reviewed again 1 week later when he reported no further improvement in symptoms. His inflammatory markers remained low with an ESR of 7 mm.
His mesalazine was increased to 4 g per day and in addition to this he was given a mesalazine enema 1 g at night.
He had a further flexible sigmoidoscopy 5 weeks after the initial endoscopy which showed normal looking mucosa and the histology was reported as showing quiescent disease.
Over the next 3 months he continued on the mesalazine orally and rectally and the prednisolone was gradually reduced. His bowel habit remained altered with the passage of partially formed motions 3-4 times per day. His joints remained painful although there were no clinical signs of synovitis and in addition to normal inflammatory markers his rheumatoid factor was also normal.
He had a further colonoscopy, which was reported as normal, and the histology was also normal. His steroids were stopped, the mesalazine was reduced to 2 g per day and he was given piroxicam 20 mg per day to treat his arthralgia.
Six months after his presentation he had regained his lost weight but still had altered bowel habit and colic. His arthralgia had settled with piroxicam.
A diagnosis of irritable bowel was considered in addition to his initial inflammatory bowel and he was treated with a mixture of mebeverine and loperamide which further helped his symptoms.
He continued to improve over the next 6 months when the mesalazine was stopped with no further worsening of symptoms.

Questions

Does irritable bowel disease and inflammatory bowel disease co-exist often and if so what clinical pointers can be used to decide which is the predominant condition?

Given that this patient resolved histologically rather quickly was the original diagnosis unsafe?

What is the role of primary care in the on going management of ulcerative colitis?

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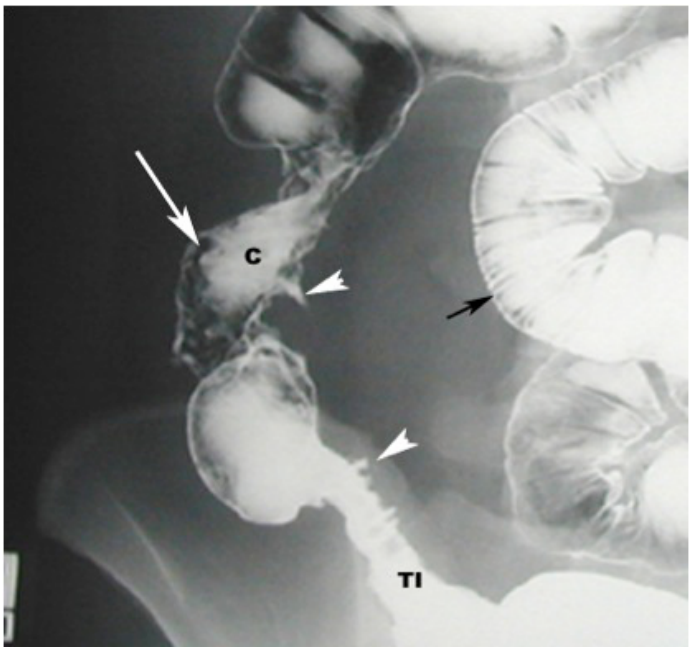
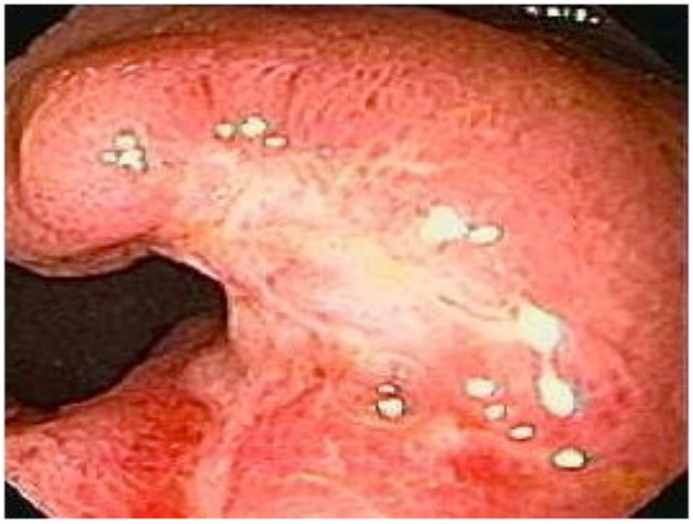
IBD case History 2

A 24-year-old factory worker presented in May 2004 with symptoms suggestive of an acute appendicitis. He went to surgery where he was found to have a normal looking appendix but the terminal ileum looked inflamed. A clinical diagnosis of Crohn's disease was made and post operatively he was started on intravenous hydrocortisone and oral prednisolone at 40 mg per day.
He had been a smoker since the age of 18 at 10 cigarettes per day and his mother also suffered with small bowel Crohn's disease.
After 2 months on a reducing dose of prednisolone he was still suffering with persistent colicky abdominal pain and on examination had a palpable right iliac fossa mass. A barium follow through was performed which showed extensive narrowing and rose thorn ulcers in the terminal ileum consistent with Crohn's disease.



He was listed for surgery but was readmitted a month later with sub-acute obstruction and he underwent an ileo-caecal resection of the diseased area. The steroids were stopped post operatively. He was seen again by his GP 3 months later with further colicky abdominal pain and loose stools and was referred back to a gastroenterologist but 4 weeks later he was readmitted with continuous abdominal pain and he was treated initially with a week of intravenous steroids and metronidazole.
He was discharged and a colonoscopy was performed as an outpatient when severe recurrent distal ileal disease was found at the anastomosis site.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Following the colonoscopy he was started back on oral prednisolone at 30 mg per day and some cholestyramine to help reduce the diarrhoea. He was also stated on weekly alendronic acid as a bone-sparing agent. He was continued on prednisolone for the next 2 months but he was unable to reduce his dose below 15 mg because of flaring of symptoms at this dose. He was started on azathioprine 25 mg per day as a steroid sparing agent but within 2 weeks had developed a hepatitis like reaction to the drug so it was stopped immediately.
Over the ensuing 3 months the steroid dose was increased and decreased according to his symptoms but no persistent control of his symptoms could be achieved and he underwent a further ileal resection and ileostomy in December of 2005 . In April of 2006 a further barium follow through showed no reoccurrence of the Crohn's and in August he had the ileostomy reversed.
12 months later he presented again with a 1 stone weight loss and further colicky abdominal pain. His inflammatory markers were marginally elevated with the ESR at 22 and C-reactive protein at 16. Prednisolone was restarted at 40 mg per day and a barium follow through showed reoccurrence of ileal disease. He was also found to be vitamin B12 deficient and was started on IM supplements. He responded poorly to steroids and within a month of re- presenting he was admitted and treated with intravenous infliximab. Within 4 weeks he was symptom free and was putting on weight.
He has continued well on infliximab since with no reoccurrence of symptoms.

Questions

Should biologicals be used in Crohn's disease before surgery is contemplated?

How long should biologicals be used if the patient appears to be in remission?

What role should primary care play in the management of patients receiving biological agents?

John Galloway

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Inflammatory Bowel Disease in children

Crohn's Disease and Ulcerative Colitis are two important diseases in a group known collectively as Inflammatory Bowel Disease (IBD). With an increasing incidence in children, research is paramount and support for families of children essential. Here we introduce you to the Crohn's in Childhood Research Association (CICRA) a charity dedicated to funding research and supporting families of children affected by this condition.

Inflammatory Bowel Disease (IBD) is still thought of by many as a condition found only in adults. However since the mid 1970s there has been an increasing incidence in children and those under 18 now account for 25% of all new cases.

IBD in children is a very complex condition that often mimics other less serious disorders in childhood and is therefore hard to diagnose. It is a chronic condition that is characterized by periodic relapses throughout life Although related, Crohn's Disease (CD) and Ulcerative Colitis (UC) are distinct disorders of, as yet, unknown cause. CD is characterised by inflammation of one or more areas of the digestive tract with normal areas of gut in between. It can occur anywhere from the mouth to the rectum, but most commonly occurs in the large or small intestine. This chronic inflammation may lead to ulceration, abscesses and strictures in the bowel. UC is chronic inflammation of the large bowel causing ulceration and bleeding. It may affect only the rectum or may spread along the whole length of the colon.

The setting up of CICRA

In the late 70's IBD in children was rare and there were few paediatricians able to treat these children without help from an adult gastroenterologist. Seeing this unexplained rise in incidence in children, and the effect it was having on their young bodies, a group of concerned parents formed the charity Crohn's in Childhood Research Association. CICRA is dedicated to creating wider awareness and understanding of CD and UC in children and young people and offers support to all sufferers and their families.

At a very early stage of the charity CICRA decided to set up a research programme. With good advice from their medical advisors, this included a Research Fellowship Training Scheme to give an opportunity for young qualified doctors to receive 3 years training in paediatric gastroenterology, both clinical and scientific. Today some of the leading specialists treating children with IBD have been trained through this scheme. With the expansion of the charity CICRA set up a PhD studentship
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scheme to encourage young scientists to obtain their PhD qualification in basic science related to children with IBD. These two schemes continue, in addition to funding other research.

Management of IBD in children

Children with IBD and their families need a great deal of support to get them through the dramatic effect that this chronic condition has on a child and the family. Their education and social life are badly affected and therefore, it is essential that they receive the right treatment and support from teams of specialists. Treatment priority is slightly different from adult practice, with not only symptom control and quality of life being priorities but also ensuring that disease control is sufficient to facilitate normal growth and pubertal development. There are many forms of treatment available from having a liquid diet (either drunk or passed to the stomach via a nasogastric tube or, if long term, a peg in the tummy). However unfortunately, even with the modern treatments available today some children have to have part of their bowel removed necessitating the formation of a stoma. Most of these children and young people are absolutely amazing in the way they cope but unfortunately some find it embarrassing and humiliating often leading to psychological problems.

Thirty years of support and research

In addition to funding research, CICRA is also providing support for the whole family. One of the most successful forms of support is the informal all-day meetings, both in London and other regions, where the whole family can come along and meet the experts. In addition to talks from medical professionals, we hear from a young person and a parent in front of a large audiences about how they cope with their condition on a day to day basis. These are followed by small discussion groups, led by professionals. A special session is arranged for adolescents only allowing them to have a very open discussion on any aspect of their condition which they enjoy and are able to make new friends.

As well as the annual London open event regional meetings have been held in Liverpool, Edinburgh and Southampton and plans are underway to visit other parts of the UK.

You may like to visit www.cicra.org or should readers require more information or if you feel we might help in other ways do contact us by e-mail: support@cicra.org

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Pharmacy-led switches in 5-ASA therapy – helpful or harmful?

The debate so far

In recent months, a number of PCTs have initiated pharmacy-led programmes to switch patients' 5-ASA (5-aminosalycilic acid) formulations. However, such programmes have raised considerable controversy, particularly among gastroenterologists. While the goal of minimising prescribing costs is an important one, there is concern that changing a patient's 5-ASA therapy may affect their disease control, with knock-on effects on quality of life, medication adherence and the doctor–patient relationship. Thus, as we move towards the era of GP commissioning, it is important to consider the true impact of such programmes. In this article, we discuss opinions on the possible effects of 5-ASA switches, and speculate on the key questions.

There can be little argument that making the best possible use of resources is of critical importance to the NHS. It is with this in mind that IBD – and particularly 5-ASA therapy – has come under recent scrutiny. Definitive data on clinically meaningful differences between the available 5-ASA formulations are lacking,[1] and consequently it could be suggested that switching patients to a cheaper formulation may reduce prescribing costs. Indeed, a number of PCTs have initiated pharmacy-led
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programmes to do just that.

However, such programmes have generated considerable controversy, particularly among gastroenterologists. The controversy centres around a genuine concern that switching 5-ASA formulations may adversely affect patient care. It is acknowledged that definitive, published evidence for an effect of 5-ASA switches on IBD control has not been established. However, anecdotal reports abound, implying that there may be a concerning number of patients experiencing flares of active disease shortly after a switch.

If there is a link between 5-ASA switching and flares, how might it arise? Both physiological and psychological explanations can be proposed. First and foremost, different 5-ASA formulations deliver the active drug to the colon in different ways, including pH-dependent release, time-dependent release and azo-bonded prodrugs.[1] These mechanisms give rise to different release profiles in the gut, and consequently there is a growing consensus that these formulations should not be considered interchangeable.[2,3] It is for this reason that the European Crohn's and Colitis Organisation recommends that 5-ASA should be prescribed by brand name.[1] A change in the release of 5-ASA into the gut might well be postulated to give rise to a change in disease control, reflecting the unique mix of characteristics and disease extent in each individual patient.

From a patient's perspective, the psychological impact of an unexpected change of medication could be substantial. Many patients, quite understandably, become anxious and concerned about such switches. Concerns about medication have been demonstrated to significantly affect adherence to medication,[4] and non-adherence to 5-ASA therapy has knock-on effects on both short- and long-term treatment outcomes.[5] Moreover, it could even be speculated that the stress these switches can cause might directly affect a patient's risk of flare (indeed, there may be some evidence to support this idea[6]).

A worrying consequence of pharmacy-led switches that should not be overlooked is the effect on the doctor–patient relationship. Naturally, maintaining a strong relationship and a high level of trust is a crucial element of care. Patients need to feel that the primary goal of the GP is to provide the highest possible standard of care, and that the GP is not affected by outside influences which puts that standard at risk. If a patient believes that their pharmacist is exerting undue influence on this trusted care, their confidence in treatment decisions could well be affected. Conversely, if the patient blames their doctor for the switch, a degree of trust will be lost – particularly if the patient is not informed in advance, or if the switch is perceived to be in the doctor's own interest and not the patient's. In the worst case, patients may associate any adverse outcomes (such as a flare) with the switch. In that case, whether the association is truly causal or not, the advocate role of the GP becomes questioned and the damage may be irreparable.

Rather frustratingly, there is currently a distinct paucity of evidence, both on the success of switching 5-ASA formulations and on the true effect of such switches on the risk of flare. Analogies may be made with other disease areas, although the applicability of these to the precise constraints of IBD is hard to establish. In addition, there are no current UK guidelines on pharmacy-led switches, although it is interesting to note that the 2009 proposal to introduce generic substitution was recently scrapped, due to concerns over patient safety and inconclusive financial benefits.[7] In this context, the financial impact of 5-ASA switch programmes should be assessed carefully, taking into account prescribing costs, implementation costs and any secondary financial impacts (e.g. additional consultations or referrals).

We can see, then, that there are a number of persuasive arguments for exercising caution in pharmacy-led 5-ASA switching programmes for IBD, but robust evidence and guidelines are not yet available. Consequently, the debate must continue. If there is indeed a possibility to conserve resources, the duty to do so must be considered.

On the other hand, if there is indeed an adverse effect on patients, it will be very difficult to justify any such programme unless the financial benefits are considerable.

Comparing IBD with other conditions – a useful analogy?

Given the lack of direct evidence on the pros and cons of pharmacy-led switching in IBD, we could turn to other disease areas for comparison. For example, a recent study found that non-consented switches of asthma inhalers was associated with damage to the doctor–patient relationship and loss of confidence in the medication.[8] The applicability of these findings to IBD must be considered carefully, to take account of the precise constraints and issues affecting each condition.

One condition that could provide a helpful analogy is epilepsy. Many patients are able to achieve good control of their symptoms, but there is evidence to suggest that medication changes are associated with a decrease in treatment success – the consequences of which may be catastrophic. As a result, generic substitution of epilepsy medications is discouraged.[9,10]

Compare this to IBD. During the maintenance phase, patients experience good control of their symptoms. However, during a flare, patients suffer considerable ill health, loss of bowel control, time off work, substantial psychological and social effects and so on[11,12] – far from being merely a bout of diarrhoea, a flare of IBD is a dramatic loss of health. That given, if switches in 5-ASA are indeed associated with an increased risk of flare, should we exercise the same caution in IBD as in epilepsy?

Dr Chris Healey and Dr John O'Malley

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Coeliac Disease, The New NHS and GP Commissioning

The Government's Health and Social Care Bill, sets the scene for future commissioning with GPs firmly in the driving seat. The preceding White Paper Equality and excellence: liberating the NHS (1) and other Government policy papers make it clear that involving patients in the commissioning process is critical to improving the quality of health services.

The radical changes proposed for commissioning may provide a real opportunity to revolutionise the approach to commissioning gastroenterological services which did not receive the attention they deserved in the past.

The PCSG is taking that opportunity by working with patient charities, Coeliac UK, Crohn's and Colitis UK and the Gut Trust, as well as the British Society of Gastroenterology to help GP commissioners with the information and tools they need to improve the quality and cost effectiveness of gastroenterological services.

Here we describe the opportunities to improve commissioning from the perspective of a single condition, coeliac disease.

Improving care pathways

How do GP commissioners effectively commission a service for patients with coeliac disease that both improves the quality of care and patients' perceptions of their care, as well as being cost effective and perhaps even deliver savings? A tall order?

That is a question a new project, funded by the Health Foundation, is seeking to answer. Coeliac UK is working with the PCSG, the BSG, Crohn's and Colitis UK and the Gut Trust to provide commissioning advice directly to GP commissioning consortia in three pilot areas.

The project will implement a methodology which will analyse local population health needs, local healthcare practitioners' and patients' views of the current service and assess the gap between current standards and national quality standards. The project will then work with the local commissioners to define a service which closes the gap, drawing on effective practice delivered elsewhere and recognising the local conditions and priorities.

In the case of coeliac disease, quality of care can improve through the uniform adoption of NICE guidelines on diagnosis of the condition and an annual review process. But even better, savings still could be made by changing the service delivery model.

Once thought to be very rare, we now know that coeliac disease affects 1 in 100 people. The disease's history as a perceived rare condition, confirmation of diagnosis made by consultant gastroenterologists and access to dietetic services has favoured the ongoing management of the condition in secondary care.

However, properly implemented, care pathways which place primary care at the centre, can improve both patients' satisfaction and quality of care. Furthermore, such an approach can prove more cost effective. The service model for management in primary care may be flexible depending on local circumstances, from a community dietetic-led annual review clinic to GP practice based review. Whatever the approach, moving management to a knowledgeable clinician in primary care with easy access to informed dietetic advice is likely to be more cost effective as well as improving satisfaction.

The project, which is due to be completed by the end of 2011 will demonstrate how services can be reviewed and redesigned, with patient views at the heart of the process,

Gluten-free food on prescription

Prescribing gluten-free food is an area very much under the spotlight by commissioners in many areas. NHS budgetary pressures are resulting in cuts in prescribing budgets and restrictions to gluten-free prescribing. In the last 12 months there has been an escalation in the number of PCTs applying restrictions. But what will be the impact on quality of care and is this the only way to find savings? Coeliac UK, backed by the PCSG, argue for a different approach.

Why are gluten-free prescriptions necessary?

In times of tough economic conditions it may be seen as an unnecessary luxury to prescribe gluten-free products.

But there are good reasons for doing so:
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- the gluten-free diet is the only treatment without which there are serious health consequences for the patient
- Studies show adherence to the diet is poor ranging from 42 to 91%. (2)
- Patients rate access to prescriptions as a key way to improve adherence
- Equivalent products in shops are around four times more expensive than their gluten-containing equivalents making access a serious issue.

Amount of products available

There is evidence that individual prescribing practice itself varies widely. Nevertheless, there are national guidelines produced in collaboration with Coeliac UK, the PCSG and the British Dietetic Association (3) setting out amounts of gluten-free food per individual per month as units based on nutritional recommendations. Originally suggested as minimum amounts Coeliac UK now recommends the amounts are treated as the norm and exceeded only on exceptional clinical grounds. Using the guidelines will help to prevent over prescribing and give GP commissioners more control over budgeting.

Type of products available

Another area that is being looked at closely is the type of products available. Coeliac UK believes it is time for the ACBS approved tariff list to be overhauled. Non-staple items such as cake mixes and some biscuits should be removed altogether - they are not essential to the diet and contrary to healthy eating policies.

However, it is important that the clinician has discretion in cases where nutritional intake is at risk. There is a case for crackers on prescription instead of bread for older patients with dental problems and biscuits or additional units for some individuals who are finding it difficult to gain weight.

Key points on prescribing

- Staple foods such as breads (including fresh bread), pasta, flours, crackers/crispbread and pizza bases listed by the ACBS should remain available.
- Cake mixes should no longer be available and sweet biscuits should only be considered in exceptional circumstances on clinical advice.
- The number of units recommended in the 2004 guidelines should be treated as the norm.

Alternative schemes

With tightening budgets Coeliac UK is looking at new ways of managing the supply of gluten-free food on prescription to provide a more cost effective service .

Pharmacy supply schemes

New gluten-free prescribing schemes are using community pharmacists to lead on the supply of gluten-free prescriptions. Initial audits of schemes in Northamptonshire and Allerdale (Cumbria) show cost reductions of 20% per patient. This is due to better control of the products and the associated costs. The schemes have been shown to save GP time and provide a better service to patients. Throughout 2010, Coeliac UK has worked with the National Pharmacy Association and the Prescribing Services Negotiating Committee, to develop a business case to support such schemes. We aim to roll this out in 2011.

Looking to the future

GP commissioning provides a key opportunity for clinicians and patients to work together to deliver quality gastroenterology services. Patient groups, such as Coeliac UK, are finding ready partners in the PCSG and other clinical groups in pursuing this work which should deliver better outcomes for all.

For more information on GP commissioning and the management of people with coeliac disease:

(1) Department of Health (12 July 2010) Equality and excellence: liberating the NHS. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_117353

(2) Hall NJ et al (2009) Systematic review: adherence to a gluten-free diet in adultpatients with coeliac disease Aliment Pharmacol Ther 30, 315–330.

(3) BDA, PCSG, Coeliac UK (2004) Gluten-free foods:a prescribing guide. http://www.coeliac.org.uk/healthcare-professionals/prescriptions

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