THE NURSES WHO SPECIALISE IN SAVINGS

Specialist nurses are far from just the ‘icing on the cake’ – in inflammatory bowel disease alone they are consistently preventing emergency attendances and ensuring the most appropriate use of services. Report by Claire Read

When Bu Hayee first reviewed the 2013 hospital episode statistics (HES) data on accident and emergency attendances for ulcerative colitis, he was convinced there was some kind of mistake.

After an initial four months in which hardly any patients with the condition arrived at his hospital’s emergency department, things abruptly changed.

“Suddenly in May to June we had this huge spike where we saw almost an attendance a day: between 20 and 30 attendances per month for those two months,” recalls Dr Hayee, clinical lead for gastroenterology at King’s College Hospital Foundation Trust.

“Initially I thought it was a bit odd, and that it was just a data error. But we looked back and went through the data manually, and actually it was true. And we realised May and June was when our single handed inflammatory bowel disease (IBD) nurse went on maternity leave, and we couldn’t cover her for those two months.”

Sure enough, when an IBD specialist nurse was reintroduced, A&E attendances for patients with ulcerative colitis fell. It is a small but striking example of the impact these nurses can have on the efficiency of care. The exact roles performed by such staff may vary, but Isobel Mason says a telephone advice line is a constant – and thus so is avoidance of unplanned care.

“Where nurses are running effective advice lines, patients with complex Crohn’s or complex ulcerative colitis – or a flare of a straightforward condition – don’t pitch up at A&E,” argues Ms Mason, nurse consultant at Royal Free London Foundation Trust and IBD nursing development manager at Crohn’s and Colitis UK.

“They call the nurse and the nurse manages them appropriately. Sometimes that’s without the patient even needing to attend the hospital, or by [the nurse] putting them into the right acute management pathway, so avoiding A&E. That’s a massive cost saving, and something that everyone wants. Nobody wants general A&E doctors having to deal with the complexities of IBD management.”

Smart thinking

It is a strong argument, but Vikki Garrick – paediatric IBD nurse specialist and GI nurse team lead at the Royal Hospital for Children, Glasgow – fears she and her colleagues are still seen as “the icing on the cake”, there solely to deliver outstanding patient care. For A&E avoidance and much else besides, she contends IBD nurse specialists should in fact be considered less as icing and more as “a fundamental part of the batter”.

“The clinical nurse specialist is not all about the delivery of patient care,” she emphasises. “It’s about designing a service that will support the patient: doing the best you can for your patients with the resources that you’ve got, and thinking smartly about how you do that.”

“There are now more than 300,000 people in the UK living with either ulcerative colitis or Crohn’s disease – the two main types of IBD – and numbers are increasing. Around 25 per cent of those cases will be diagnosed in childhood or adolescence. While the exact symptoms vary, these conditions are always chronic and involve periodic exacerbations. Such flare-ups can include severe abdominal pain and frequent passing of watery stools, sometimes with blood.

These are disturbing and unpleasant symptoms, but rarely best managed in an emergency setting. The problem is that a third of patients report no access to an expert IBD nurse, and 63 per cent of services do not have enough nurses to meet national standards. That means A&E or the GP becomes the point of call.

As a healthcare manager, a Crohn’s patient, and a trustee of Crohn’s and Colitis UK, it is a state of affairs into which Amanda
Quincey has a particularly keen insight. She recognises that, for a commissioner or for a provider chief executive with multiple priorities, it can be difficult to decide to spend money on an IBD specialist nurse rather than on something else which may have a higher profile.

“But there’s evidence starting to come through that shows you do prevent admissions by having that swift access to advice, support and clinical expertise,” she points out. “And as someone who’s managed services, your front door is critical – you have to keep that flow moving through the hospital.

“So if you can get expert nurses to assess patients and either keep them at home or move them along quicker, it frees up the front door for those emergencies that need support from other areas.”

**Benefits of investment**

Primary care also benefits, she suggests. “The average GP has perhaps 1,500 patients on their list, will only have seven patients on their system who has IBD, and will only see a new Crohn’s diagnosis every seven years. That’s where specialists within nursing really can pay dividends.”

At Crohn’s and Colitis UK, the belief in the value of these nurses is such that campaigning for more is at the heart of the charity’s strategy. The More IBD Nurses – Better Care campaign aims to get to a point where 95 per cent of the organisation’s supporters have access to a named and appropriately trained IBD nurse.

David Barker, the charity’s chief executive, admits it’s obvious for a patient organisation to support a staff group so often associated with excellent care. But he wants holders of purse strings to understand the benefits of investing in specialist nursing go beyond high quality care.

“There is no money in the NHS – we all know that, and all know it’s about how do we get more for the same, or in some cases more for less. Service redesign is critical to that, and where we’re seeing real success, IBD specialist nurses have sat at the heart of that.”

He continues: “There are just so many benefits on so many levels to having good specialist IBD nurse provision. If you look at the power of a nurse in supporting patients, saving money, avoiding admittance to hospital, avoiding inappropriate outpatient appointments, avoiding A&E, there is a very, very powerful case to be made for the difference they can make.”

If you are a hospital chief executive, you may recently have received an email about the care your trust offers for inflammatory bowel disease. Maybe you’ve received messages from several patients. Since May 2016, over 6,000 emails from 1,200 people have been sent to trust heads up and down the country.

Chances are you don’t often receive letters about IBD. We know that it’s probably not a condition which is typically high on the list of those commanding your attention.

Yet the illnesses covered by that generic term – most notably Crohn’s disease and ulcerative colitis – are on the increase. More than 300,000 people in the UK now have an IBD diagnosis.

These are long term conditions, unpredictable in their course. And, significantly, if those with IBD don’t get the right care then they are likely to be users of unscheduled care at your hospital.

That means A&E attendances and emergency admissions, putting pressure on your already stretched services and finances. It is estimated that care of IBD patients costs the NHS £470m a year, with lifetime medical costs comparable to those for diabetes and cancer.

At Crohn’s and Colitis UK, we know specialist nurses are key to reducing these costs and avoiding these outcomes. So do our supporters: the ones who have been emailing you in recent months.

With an IBD specialist nurse in place, those with the condition have a point of continuity – a clinical expert who can offer close monitoring, timely advice and support, and brokering of care across sectors. That keeps patients out of hospital.

For you as a senior leader, the result is cost savings. Consider that specialist nurses are also ideally equipped to lead service redesign and there are more efficiency savings still.

This special report explores the value offered by IBD specialist nurses – something we are also emphasising through our More IBD Nurses – Better Care campaign.

We hope the articles in these pages will convince you such posts represent an investment in greater efficiencies and excellent patient care.

If they do, and you would like help with local service development and business planning, please get in touch. We are ready to help – and thousands of patients are willing you to put this on your agenda.

Isobel Mason, nurse consultant at Royal Free London Foundation Trust and IBD nursing development manager at Crohn’s and Colitis UK

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SUPPORTING COST EFFECTIVE INNOVATIONS IN TREATMENT

Specialist IBD nurses are key to ensuring cutting edge biological therapies are used in a way which benefits both trust and patient, as Claire Read explains

Review the drugs on which the NHS now spends most and a theme quickly emerges. Of the top 10 highest spend medicines, nine are biologics: those molecularly complex “blockbuster” drugs which are made from living cells and which target the mechanism of a disease.

This is the sort of precision medicine which has most commonly been associated with cancer. It may come as a surprise, then, to learn that the drug on which the NHS is now spending most is not in fact used for treatment of that disease.

Adalimumab – on which £416m was spent last year alone – is actually used to treat inflammatory bowel disease (IBD), along with arthritis. So too is infliximab, which occupies slot number five. Together, they contribute to the health service spending 15 per cent of its budget on medications and treatments – some 30 per cent higher than five years ago.

For people with IBD, biologics can be nothing short of life changing, relieving symptoms which have previously proved resistant to treatment. But it is clear the drugs do not come cheaply.

The issue goes beyond the price tag. Before they can be administered – by injection in the case of adalimumab; by infusion for infliximab – a large amount of preparatory work is needed.

Explains Isobel Mason, nurse consultant at Royal Free London Foundation Trust and IBD nursing development manager at Crohn’s and Colitis UK: “There is really complex screening to make sure a patient is safe to have the treatment, then making the case with funders to get the money for the drug, then counselling the patient and organising the actual administration.”

The work doesn’t stop once treatment begins. Regular and careful monitoring is required, explains Charlie Murray,

THE GASTROENTEROLOGIST’S VIEW

“The difference between having an IBD nurse or not is effectively a complete change in practice. I often joke that all of the really hard work within the IBD service is done by the nurses – they’re the ones organising the medications, they’re the ones supplying that deep background information to patients [to help them understand and cope with their condition]. Without them, you could manage a chronic condition like IBD badly, but to manage it well is impossible.”

Charlie Murray, consultant gastroenterologist and clinical director for gastroenterology, Royal Free London Foundation Trust

‘When the pathways are in place and they work well, the cost of drugs is dramatically reduced by specialist nurses’

consultant gastroenterologist and clinical director for gastroenterology, Royal Free London Foundation Trust. It is work he says would be impossible without his IBD specialist nursing colleagues.

“They help to a huge degree with the clinical governance around what are very complex treatments and follow ups.

“A lot of our treatments in IBD will be immuno-modulatory, so they will affect the immune system. They can affect blood tests, they can affect other bodily systems, and so that requires follow up and watching – making sure blood tests are done at the appropriate times, and making sure there’s timely follow up and review of patients to make sure they’re on the right medications, not on medications for too long, and that we get all the funding streams in place for high cost therapies.”

Getting it right means high cost drugs are used in a way which ensures best value for money. “When the pathways are in place
and they work well, the cost of drugs is dramatically reduced by specialist nurses,” says Ms Mason.

“There’s no loss of money because we’re paying for patients who shouldn’t be on the drugs any more just because nobody’s reviewed them, or because a breakdown in communication means a funder is no longer paying for a treatment. Day in, day out, advanced nurses are making sure patients are on the right drug at the right time.”

At many trusts, they are also making it possible to introduce significantly less expensive versions of biological therapies. In 2015, a biosimilar version of infliximab came on to the UK market. The “similar” is an acknowledgement it is not possible to completely copy the complex molecular structure of the original, but a demanding licensing process ensures there is no clinically meaningful difference in efficacy.

The only practical difference is the price, which is significantly lower. A biosimilar adalimumab is now on the horizon, and as increasing numbers of originator patents expire – across many therapy areas – it will be joined by many others.

York Teaching Hospital Foundation Trust switched to biosimilar infliximab in September 2015. A year later, savings of £450,000 had been amassed. According to Stuart Parkes, deputy chief pharmacist at the trust, IBD nurses were central to the success of the switch. “They were important in providing information to patients, both over the telephone and within clinic visits, and also speaking to staff at the day unit where the infliximab infusions are administered.”

For Helen Terry – director of policy, public affairs and research at Crohn’s and Colitis UK – supplying that information is absolutely key. A switch is not a simple process, and can stir up deep emotions for some of those on biologics.

“For patients who have been on a very long, very painful, very debilitating journey to the point where they’ve been prescribed infliximab and found a drug that’s actually worked for them, then the fear of going back to where they were pre-infliximab is very real,” she points out.

Some patients, if that anxiety isn’t addressed and acknowledged and understood, feel very threatened by this prospect of switching.”

“You have to counsel the patient properly – and this is not a 10 minute clinic appointment; it’s a good 40 minutes spent with the patient to counsel them properly,” agrees Karen Kemp, lead nurse for IBD at Central Manchester University Hospitals Foundation Trust. The trust is now giving the biosimilar version to any patient who is new to infliximab – all have an appointment with an IBD specialist nurse before treatment begins – and are expecting cost savings as a result.

The irony is that the savings do not automatically go to the organisation doing the ground work to make them possible. As high cost drugs, the bills for adalimumab and infliximab are footed by clinical commissioning groups (CCGs).

Yet to switch successfully requires work from the provider sector. It is why many areas are negotiating gainshare arrangements, in which savings are split between provider and commissioner.

In York, such an arrangement has made it possible for the trust to employ an IBD specialist nurse at its Scarborough site.

“It made the case for that post,” explains Mr Parkes. “I think we would have been going for that model anyway, because we only had a nutrition nurse in Scarborough who was doubling up a role to see some of the patients there. But certainly the case has been made easier by the fact we’re saving on the infliximab – I think the savings we had on the biosimilar were the enabler.

“Having the nurse at Scarborough means more patients from that area can be treated there rather than having to come 40 or 50 miles to York, and that they have a specialist who’s looking after their care.”

It’s a similar story at Royal Free London Foundation Trust, where savings of £2.5m over two years are anticipated from the use of biosimilars in gastroenterology.

“We have an agreement with the local CCGs that there will be some gainshare, so some money savings would stay with us and that therefore the trust would allow us to appoint a couple of extra IBD nurses,” reports Dr Murray.

He acknowledges the appointments are made on the basis of a limited timescale, and that the money won’t be present forever.

“But the way we’ve always felt about our service is that we don’t think it will be difficult at all to justify how much the nurses do, and that once they’re in post they will become indispensable.”

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**THE PATIENT’S VIEW**

“You can just pick up the phone to a specialist nurse and say: ‘You know what, I think I might be having a flare.’ And the treatment can be in place within days to prevent anything further down the line. When you look at the long term cost savings – the price per head of an admission per night compared to an IBD nurse’s salary – it just makes perfect sense to have these specialist nurses.”

Bev Davies, head of IBD patient panel, The Shrewsbury and Telford Hospital Trust
BRINGING IT ALL BACK HOME

Shrewd service redesign by specialist nurses can lead to greater efficiency for providers and better care for patients

When the Five Year Forward View encouraged moving care out of hospital, Sharon Gethins had reason to celebrate being ahead of the game. An inflammatory bowel disease specialist nurse at University Hospitals of Leicester Trust, Ms Gethins has been seeing patients in community settings for over a decade.

The setup began when she and her colleagues realised the existing system just wasn’t efficient for patients or the trust. Consultant clinics were swamped, and many patients forced to travel long distances for appointments.

“We decided bringing services closer to people’s homes would be far better,” remembers Ms Gethins. “We were doing it through telephone clinics, but there was still a group of patients who needed a face to face consultation.”

So each month since 2005, Ms Gethins has run IBD clinics at two local community hospitals. As an independent nurse prescriber, she is even able to introduce new drugs for patients and offer appropriate counselling.

“We don’t need the doctor any more for that, and it’s all being done near the patient’s home instead of in the teaching hospital.”

It’s just one example of how IBD specialist nurses can identify service redesign opportunities – and get on with delivering change.

Another comes in the form of a rapid access clinic at Stockport Foundation Trust. In the face of patients waiting an average of 38 weeks for a diagnosis of inflammatory bowel disease, lead IBD specialist nurse Rachel Campbell was determined to create a better system.

“There is nothing worse than having a patient stuck in primary care waiting for a referral in [to a consultant], then waiting again to be seen by that consultant, and then waiting again to be seen for an investigation,” argues Ms Campbell.

“And in that time they’re probably going back to the GP multiple times for flare up symptoms, and possibly into the emergency department, which costs money. So this idea came about so that we could improve the flow, diagnose patients quicker, and save some money in the process.”

GPs seeing patients with bowel problems now have access to an algorithm which helps them ensure use of the best pathway. If test results suggest possible IBD, the GP is able to refer straight to Ms Campbell, who triages patients and brings them into the rapid access clinic.

“I go through everything with the patient, much as the consultant would do,” she explains. “And as I’ve got advanced nursing experience, I can order any procedure that needs ordering.”

Since setting up the clinic – which took Ms Campbell only three weeks from idea to implementation – the average waiting time from referral to treatment has dropped to nine weeks.

There have been cost savings too. “Just by doing this clinic, I’ve brought in five patients rather than them going through A&E, so that was a £9,000 saving. And the difference between me doing a clinic and a consultant doing a clinic for the first 100 days of the project was about £4,000. It’s putting my skills to best use as well,” says Ms Campbell.

New IBD pathways have also led to cost savings in south London. Lambeth CCG was keen to ensure appropriate use of high cost drugs in IBD, as well as excellent patient care. As a first step, a patient group was set up to discuss experiences.

“The IBD nurses were absolutely brilliant in helping us to do that,” remembers Vanessa Burgess, chief pharmacist and assistant director of commissioning.

Four new pathways were designed, with a view to diagnosing disease early and managing any exacerbations promptly. Says Ms Burgess: “The big thing for us was around not escalating treatment, so catching a disease early and getting a patient on the right treatment. You then also get less surgery, which is hugely expensive.”

According to Bu Hayee, clinical lead for gastroenterology at King’s College Hospital Foundation Trust, “in every pathway there is a central role for the IBD nurse.”

The team had projected the new setup would save £250,000. “But we’ve actually managed to save nigh on £800,000 in terms of operational costs, drug costs, avoided admissions, and reduced length of stay,” he says.

“Even with that £250,000 projected saving, that’s paid for our IBD nurse many times over. There is this false economy that because [an IBD nurse] is a salary, people see it as an expense that appears on the bottom line. But when you take everything into account, the savings are many times greater.”

[Image of nurse with patients and documents]
SUPPORT TO SELF MANAGE

The support of a specialist nurse can equip IBD patients to better manage their condition, thereby reducing dependency on hospital services. Claire Read reports

Among the many cards in Bev Davies’ purse is one given to her by her IBD specialist nurse. On it are five symptoms, a phone number and a simple message: if you experience any of the symptoms, call the phone number. For Ms Davies, that card is a crucial part of being able to effectively manage her inflammatory bowel disease.

“It’s so important in terms of self-management, because you know what to look out for,” she explains. “Should we have a reaction to our medication, should we have any concerns, or if we think we’re having a flare up, the first thing that we know we should do is pick up the phone to speak to our IBD nurse, and she will be there. She’s the first point of contact, and her prime job is to keep us well.

“Knowing those five key things can save an awful lot of distress, and eventually money in terms of resources,” she argues.

Ms Davies has lived with ulcerative colitis since the age of 11. But she feels having access to an IBD specialist nurse in recent years has finally helped her to cope with it well.

“It is quite a lonely and embarrassing illness for so many people, because a lot of the time you do have to shut yourself in the toilet. I did cut myself off from a lot of people because I didn’t really know how to deal with it in the same way I do now.”

Moeed Majeed also credits an IBD specialist nurse with helping him manage his condition. When he was diagnosed with Crohn’s disease at 19: “I had no idea what it was. So my first question was how do I cure it – obviously not understanding [that it is a chronic condition],” he remembers.

“I had to do my research, and if patients have got questions the specialist nurses are more than happy to answer: they’re an encyclopaedia of knowledge. If ever I had any questions, they would either give me the answer or point me in the direction to find the answer.”

This is a central part of an IBD specialist nurse’s role, says Julie Duncan. “Generally a newly diagnosed patient will come to see the IBD nurse for a comprehensive discussion about the disease,” explains explains the IBD nurse manager at Guy’s and St Thomas’ Foundation Trust.

“We discuss how you manage it, how we would expect the course to run. We give education about medicines – things like this is a drug you’re going to take long term, therefore you need to plan ahead; you need to make sure you don’t run out.

“But also how to manage a flare: OK, you’re on these medicines, you can adjust your dosage, you can add in other medications, if you are having these sorts of symptoms you’ve got to get in touch with us because we need to organise investigations. And we can decide on the advice line whether you need to come to clinic, or whether you can manage that situation with support at home.

“It’s knowing who to contact when; how to get in touch with the secretaries, or the appointments team, how to get in touch with the IBD nurse advice line,” she says.

“That brokering of care and support of self care also represents a far more sustainable way of caring for patients with long term conditions. At University Hospitals of Leicester Trust, a self management programme for patients with IBD is thought to have released almost £150,000 over five years.

THE PATIENT’S VIEW

“What specialist IBD nurses do is so important to people going through this journey, and because they’re so good at it I think it’s taken for granted. But inside my soul and my heart I owe them so much. I can’t imagine doing this whole thing without them – I think there would be a massive disconnect between the consultants and patients. It smooths out the whole journey between the two.”

Moeed Majeed

THE NURSE MANAGER’S VIEW

“I think specialist nurses often hold the whole thing together – they’re the pivot in the team and help coordinate journeys across the full patient pathway.”

Julie Duncan, IBD nurse manager at Guy’s and St Thomas’ Foundation Trust