RESEARCH

Implementing a self-management strategy in inflammatory bowel disease (IBD): patient perceptions, clinical outcomes and the impact on service

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ABSTRACT

Introduction Patient self-management and its service integration is not a new concept but it may be a key component in the long-term sustainability of inflammatory bowel disease (IBD) service provision, when considering growing disease prevalence and limited resources.

Methods The IBD team at the Royal Alexandra and Vale of Leven Hospitals in the Clyde Valley region developed a self-management tool, called the 'flare card'. Patients were asked to complete a questionnaire which reflected their opinion on its viability as a self-management intervention. In addition, its utility in terms of service use over a 10-month period in 2016 was compared with a similar cohort of patients over 10 months in 2015.

Results Patients overall felt that the 'flare card' was a viable self-management tool. Positive feedback identified that the intervention could help them aid control over their IBD, improve medication adherence, reduce symptoms and reflected a feeling of patient-centred IBD care. The comparison between 2015 and 2016 service use revealed a significant reduction in IBD and non-IBD service usage, Steroid prescribing and unscheduled IBD care in the flare card supported cohort.

Conclusions IBD services must continue to adapt to changes within the National Health Service bearing in mind long-term sustainability and continued care provision. The 'flare card' goes further in an attempt to optimise Crohn's disease and ulcerative colitis management by harmonising clinician evaluation and patient's self-initiation of therapy and investigation.

INTRODUCTION

The adoption of patient self-management is a growing area of service development for inflammatory bowel disease (IBD) services.¹ Examples of disease education programmes may lead to positive outcomes.² If patients have education to understand the appropriate course of action to take when they develop symptoms, then there is a greater chance of remission maintenance.³

Furthermore, the increasing prevalence we are seeing in IBD⁴ will mean the sustainability of IBD services using historical six monthly or yearly return models of out-patient care is questionable. There is limited evidence on the provision of self-management which supports self-initiation of therapy in IBD,⁵ despite the fact that patients seem to prefer flexible follow-up which incorporates medicine management.⁶

The IBD team, at the Royal Alexandra and Vale of Leven Hospitals—NHS Greater Glasgow and Clyde, has worked to develop a high-quality self-management intervention. It is believed to safely promote early initiation of IBD therapy, in a reactive manner to patient symptoms and equally have a significant impact on service provision. We used this to enhance our approach to IBD nurse 'return' clinic appointments to evolve from the historical IBD model of nursing service delivery.

METHODS

We introduced 'the flare card' which is a fold-out wallet-sized booklet and which

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aims to guide patients as to appropriate action to take if they develop symptoms.

We sought to collate data regarding the quality of the intervention from the patient's perspective. The first consecutive 80 patients booked for routine review in January 2016 at our nurse-led clinics were sent the flare card in December 2015 before they attended. They were asked to read the flare card and complete a feedback questionnaire based on self-management theory. They were also asked to comment on whether this intervention would be useful in an electronic format. A section for comments was also added to the questionnaire. Provided patients were happy and felt informed on how to use the flare card, they were not re-booked for a routine return appointment at a nurse-led clinic. Consultant gastroenterology clinic appointments were in place as before. As per normal practice all patient contacts were recorded electronically.

The flare card is designed to help educate patients in symptom identification and to inform them to gain objective evidence, with assistance from primary care to allow a safe increase of therapy. The flare card is linked to the telemedicine system we have in place for patients with IBD.⁷

The second part of the study was observational, designed to monitor the application and utility of the flare card between January and October 2016. The effect on patient outcomes was measured over 10 months. We recorded all patient contacts on the electronic system.

To determine the impact on IBD service, we compared the 2016 data retrospectively with the first consecutive 80 patients attending IBD nurse-led clinics in 2015. These patients did not have exposure to the intervention and clinical outcomes were gathered for 10 months equally. Data were collated to establish the

amount of phone calls, return IBD appointments and other use of hospital facilities. Both cohorts were compared to determine whether there were any differences, following introduction of the flare card. A cost analysis was carried out in addition, to show any financial benefits.

RESULTS

In the 2016 cohort, 41 (51%) patients returned a feedback questionnaire. The feedback questionnaire used a simple five-point Likert scale. Points were allocated (1) *strongly agree*, (2) *agree*, (3) *undecided*, (4) *disagree* and (5) *strongly disagree*. The patients were asked four questions which reflected broad themes linked to self-management of health: disease control and empowerment, medicines adherence, symptom reduction and patient-centred care.⁸ Similar studies have used these as measurements to determine the success of a self-management tool.⁹ The results are shown in [figure 1](#).

Eighty-seven per cent of patients scored in 'strongly agree' or 'agree' categories. Twelve per cent of patients were undecided about the impact of the flare card on the linked domains. Finally, 1% of patients did not feel that the flare card helped them feel involved in their care. A fifth question was added to determine whether patients felt that the flare card would be useful as an electronic version. The results are shown in [figure 2](#). In addition, patients were given an option to leave a free text comment. Ten patients (24%) left written feedback, which is detailed in full in [figure 3](#).

The data from the 2016 flare card supported cohort showed 13 contacts with the service made after patients had initiated self-management based on the flare card instructions. The primary reason for those patients making contact was due to a change in bowel habit, with blood and loose stools evident as

Figure 1 Patient feedback on the effectiveness of the Flare Card.

Figure 2 Patient feedback on whether an electronic Flare card would be worthwhile.

symptoms (69%). One patient had early identification of a campylobacter infection and was treated with antibiotics. Abdominal pain accounted for nearly a quarter of patients (23%). Patients also reported side effects to IBD medicines (8%). Twelve out of the 13 patients required their long-term therapy to be escalated following contact, which was out with the realms of self-management. This was following reassessment with endoscopy or imaging where appropriate. A summary is shown in [figure 4](#).

At the time of telemedicine contact, all patients with ulcerative colitis, who required a dose increase (9/13) initiated an increase in their mesalazine dose and/or added in rectal mesalazine as per the flare card instructions. Furthermore, 13 patients (100%) had bloods updated at the General Practitioners (GP) surgery, triggered by the flare card pathway. This represented a full blood count, liver function tests and C reactive protein (CRP) recorded on the electronic system. Nine out of 13 patients (69%) had stool cultures and calprotectin results available for interpretation.

[Figure 5](#) shows comparative results between the two cohorts indicating a significant reduction in both IBD nurse appointments (87%) and IBD phone calls (74%). Steroid prescriptions were reduced by 77%.

No patients required attendance at the emergency department or had an episode of admission related to IBD in 2016. Conversely, in 2015, these accounted for 11% of service use. An independent t test comparing the two groups and assuming equal variances was carried out on Microsoft Excel which showed p values of <0.05 for all five groups of service utilisation. A cost analysis was added to show the financial advantages of this type of strategy, shown in [figure 6](#) which reflects an average cost reduction of 94% based on a similar cohort of patients over the previous year.

DISCUSSION

The concept of self-management strategies has been explored in chronic disease previously.¹⁰ In terms of IBD self-management, current evidence should translate to support its use. There is not currently one model or strategy that has been identified as best practice. There is obvious variability across health boards and nationally. There is a pressure on IBD resources currently worldwide and it may be that this is why. Many services are still building service foundations and self-management could be further down the priority list.

Based on the feedback from the quality questionnaire, the majority of patients agree that it is a useful

'Excellent information about treatment doses – I wasn't too sure up until now'	'Generic Dietary advice would be great in future versions of this card'
'It would have been great to have this when I was just diagnosed'	'Twitter and Facebook integration if it becomes an app please!'
'I would like to access my care records with this'	'It is an excellent resource for new patients'
'Younger Patients might like the App more than me'	'If this could link in with my IBD results – I would love that'
'Trusty companion Card – lets me know what to ask my GP to do'	

Figure 3 Patient feedback on the Flare Card.

Self-Management initiation - Reasons for patient contact n=13		
Symptoms		
Loose Stools with Blood	9/13	69%
Abdominal Pain	3/13	23%
Side Effects related to IBD medicines	1/13	8%

Figure 4 Reasons for patient contact.

Figure 5 Comparison between 2015 and 2016 cohorts.

intervention. ‘Flare card’ appears to be easy to use and an effective self-management tool. In this way, care can focus on adherence and use of medicines when a patient is in remission and in the same way, an adjustment of the same, when a relapse occurs.¹¹ This is shown in [figure 7](#).

It has been well documented that IBD services should have telemedicine services underpinning them¹² which enables patients to have direct access to specialist advice and assessment. An IBD advice line is normally staffed by a specialist nurse. The practitioner may elect to prescribe medicines, order investigations, book outpatient consultation or optimise current treatment over the phone. The flare card is enhanced by this parallel service.

The focus of IBD care, after all, should be to identify relapse and make swift change to treatment and this provides the best chance of optimal IBD outcomes such as disease-free remission, prevention of surgery, stricture, fistulae, cancer and anaemia.¹³

Self-management will not suit all patients. It appears to be more applicable to patients who are able to retain and apply accurate information to suit their symptoms. Limitations for this type of strategy may include young or elderly patients, patients with mental health disability or extreme anxiety. These patients may well require more intense face to face follow-up, along a traditional IBD nursing pathway.

It is also important to note here that a considerable amount of patients with IBD may report symptoms which are not driven by inflammation.¹⁴ One skill of an IBD practitioner is to investigate with subjective

and objective markers to rule out what might be constipation, infection or diarrhoea which is not driven by disease.¹⁵

Scoring systems for disease activity can be useful; however, a combination of objective and subjective information appears to be far superior in combination than one alone. This approach is in keeping with treat-to-target strategies.¹⁶ The flare card allows patients to translate symptom threshold into practical steps, the parameters were set at 3 days of corresponding symptoms. These are based on framework already developed scoring systems such as Harvey-Bradshaw, Mayo scoring and Crohn’s Disease Activity Indices.¹⁷ The benefit of this system is that it does not require calculation or interpretation of result by a patient. It is further enhanced as an example of collaboration between patients and the IBD clinicians caring for them.

By instructing patients to have investigations such as blood and stool specimens carried out on the basis of symptoms as opposed to scoring systems alone provides the clinician with objective evidence of disease activity. CRP is used by clinicians in tandem with albumin to determine a patient’s disease activity. Faecal calprotectin, an increasingly used faecal biomarker, can also predict and determine relapse.¹⁸ Stool cultures are essential in separating infective causes for patient’s symptoms from true IBD relapse. There is a need to have a balance between scores that can be interpreted by IBD clinicians, in a way this can be translated in language that patients can understand. This is reflected in the first part of the flare card displayed in [figure 8](#).

Comparative IBD Contacts, 2015 versus 2016	2015	No.	2016	No.	(Cost) % Reduction
IBD Return Clinic Appts (£140)	£8960	64	£1120	8	(7840) 87%
IBD Phone Calls (£23)	£1173	51	£184	13	(989) 74%
IBD Related Admission (£2754)	£11016	4	£0	0	(11016) 100%
A+E Attendance (£590)	£590	5	£0	0	(590) 100%
Totals	£21739	124	£1304	21	(20435) 94%

Figure 6 Cost benefit analysis.

Mesalazine - Normally, you will be prescribed one of these preparations. However there are other Generic brands of Mesalazine. Each has a different dose and each releases differently in the bowel. There are two doses, 'Maintenance' - when you don't have symptoms and 'Treatment' - when you do.

Salofalk - Dr Falk

Granules/Tablets – Maintenance is 1.5 Grams once a day. Treatment is 3 Grams once a day.

Asacol - Actavis

Tablets – Maintenance is 2.4 Grams once a day. Treatment is 4.8 Grams once a day.

Mezavant XL - Shire

Tablets – Maintenance is 2.4 Grams once a day. Treatment is 4.8 Grams once a day.

Pentasa - Ferring

Granules/Tablets - Maintenance is 2 Grams once a day. Treatment is 4G once a day. It's perfectly safe for you to increase your Mesalazine therapy to 'Treatment', when you have symptoms (As indicated above) but if you do, we ask that you increase therapy for 6 weeks.

Rectal Therapy – Mesalazine Suppositories and Enemas

If you have a supply of these and are familiar with how to use them, it is safe to institute these, normally nightly for two weeks, to help control symptoms.

Symptoms should improve after a week or two, but if they don't, get in touch with your IBD Specialist Team.

If your Symptoms settle, then after the 6 weeks, you can reduce the mesalazine down to the 'maintenance' dose.

Figure 7 Mesalazine dosing regime.

The British Society of Gastroenterology guidelines¹⁹ on IBD management suggest that patients should have a yearly review. This is also promoted by the IBD standards document and the recently published National Scottish IBD Blueprint.²⁰ In many ways, IBD service should benchmark against these guidelines for out-patient care; however, the reality for many services is that this presents difficulties in achieving this and sustaining it. This would appear to follow a traditional pathway and it could be postulated that service for the future will need to adapt.

Our own database consists of approximately 3000 cases of IBD between our two sites, the Royal Alexandra and Vale of Leven Hospitals, NHS greater Glasgow and Clyde Health Board. Our incidence of IBD cases from January 2015–2016 was 124 new cases between both sites. These two sites have a combined catchment of 300 000 patients.²¹

Ergonomically, given the volume of patients under this catchment area and the current capacity available, it is unachievable to facilitate a yearly, face-to-face review for the IBD population in its entirety. A new pathway, which allows patients and clinicians flexibility to receive and provide optimal IBD care, surely must be the future service model.²² This system

● What can YOU do, if you think IBD symptoms are returning or have become uncontrolled?

● A relapse/exacerbation of your inflammatory bowel disease is often called a 'Flare'

● If your bowel habit has been settled and begins to change, it might be that your IBD is becoming active again.

If Your Bowels have been opening more than 5 times a day (In 24 hours) for more than 3 days.

If You notice blood/slime in your stools for more than 3 days.

If Your stools are loose or you have diarrhea that persists for more than 3 days.

Or a Combination of the above?

** If you have abdominal pain and nausea that persists we would advise that you be assessed quickly by your GP*

Figure 8 Symptom recognition.

should allow for empowerment of patients to be involved in their own care, while being proactive in seeking advice and self-initiating therapy when appropriate.

As evidenced in this study, by providing an alternative pathway for patients to follow, substantial reductions can be made in face-to-face appointments and telephone calls, allowing for time to facilitate review of patients who are symptomatic and require urgent attention.

It highlights that disease-specific education for patients should involve symptom manifestation and relapse prevention. The flare card meets these educational needs. It is not yet evident whether this type of strategy can impact unscheduled care in the long run; however, if it seems at least based in the first year's results, that avoidance of unnecessary admission, accident and emergency and non-specialist consultation can well be avoided.²³

The most significant implication of this work is improved clinical outcomes. It would appear that if patients are well informed about their disease and are aware of the importance of early detection of symptoms, then long-term goals can be met. It should not be ignored that while clinically effective, there are associated benefits with service provision directly. The sustainability of long-term service planning can be enhanced by financial benefits reaped indirectly.

CONCLUSIONS

Given that IBD is a chronic condition, follow-up is essential. Months or years can pass between relapses. Reporting of symptoms should be prompt and accurate to allow detection and confirmation of relapse. A combination of both objective and subjective markers is vital. Treatment should be started accurately and quickly where indicated and patients can play a significant role in this.

This observational study suggests that patients have confidence in a self-management approach and that it is economically attractive. There are limitations of this study. Although two similar patient cohorts were chosen for comparison, they were not randomised. The data from the previous cohort were retrospective, which exposes the data to confounding factors. Furthermore, return rates for the questionnaires were proportionally low, but are in keeping with other studies.

Nevertheless, the flare card can be safely used to allow patients to interpret their own symptoms, and initiate their own therapy in parallel with primary and secondary care teams. It may be a utility that other IBD centres could adopt.

For further development, an electronic version of the flare card seems appropriate. With this format, additional information can be provided on the specifics of blood testing, values and results, as suggested by several patients.

Significant of this study

What is already known on this topic?

Evidence has shown that self-management strategies can be an effective way to streamline clinical follow-up in inflammatory bowel disease (IBD) service. The specific type of follow-up model that is best used is yet to be determined.

What this study adds?

The flare card is designed to allow patients to 'self-initiate therapy' in a safe, straightforward manner. Our tool merges clear information that patients can understand and empowers them to take control of their disease. Both primary and secondary teams can benefit from this approach, helping patients mitigate the unpleasant side of disease flare, while reaping the benefits of service efficiency.

How might it impact on clinical practice in the foreseeable future?

We acknowledge that this tool will not be suitable for every patient; however we believe that integration of the flare card into IBD services may be a step towards achieving a sustainable IBD service for the future.

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Contributors SIS, AJB, GDN, SL: statistical analysis and drafting of manuscript. SIS, AJB, GDN, SL: project conception, data collection, synthesis and redrafting of manuscript.

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