RESEARCH

A dedicated inflammatory bowel disease service quantitatively and qualitatively improves outcomes in less than 18 months: a prospective cohort study in a large metropolitan centre

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Abstract

Introduction Maintaining high efficacy and quality of care in inflammatory bowel disease (IBD) management is a priority. The authors examined whether the introduction of a formal IBD Service (IBDS) positively influenced outcomes for their patients.

Methods In 2007–2008, all IBD patients attending the Royal Adelaide Hospital were surveyed regarding clinical/demographic data, IBD knowledge, quality of life, mental health and satisfaction. Survey responders were re-surveyed ≥ 15 months later.

Results 162 responded to survey 1 and 81 again responded to survey 2. Within the responders, 61% had Crohn's disease and 48% were men. Compared with survey 1, the proportions of patients with improved knowledge, adherence, satisfaction with care, QoL (≥ 5 points), anxiety and depression scores were 63% (95% CI 51 to 73), 62% (95% CI 50 to 72), 65% (95% CI 54 to 76), 42% (95% CI 31 to 54), 52% (95% CI 40 to 63) and 43% (95% CI 32 to 55), respectively. When comparing survey 2 with survey 1, reductions in hospitalisation (48% vs 30%, $p=0.02$), courses of corticosteroids and opiates (mean 1.63 vs 0.91 and 1.00 vs 0.61, both $p<0.05$) and overall medications (5.63 vs 4.65, $p<0.05$), were seen. Fewer 2009 non-responders required hospitalisation (53% vs 21%, $p<0.001$), suggesting a 'cohort' rather than 'responder-specific' effect.

Conclusions The introduction of an IBDS resulted in improved patient outcomes with significant reductions in negative markers for IBD morbidity including: hospitalisations,

polypharmacy, steroid and opiate use. Despite increased costs in additional staff, these measures are likely to be cost effective.

Introduction

Maintaining a high standard in the management of inflammatory bowel disease (IBD) patients is an important priority for all hospitals. However, little published data on the best way to provide this care, in terms of healthcare structure, rather than clinical trial data of individual agents exists. As mortality is not generally increased in IBD, optimising quality of life (QoL) is important and, realistically, this must be done in an efficient and cost-effective manner as healthcare resources are finite in all countries.¹

IBD is a chronic illness characterised by phases of remission and relapses which may require recurrent hospital admissions and at times, major surgery. Sufferers are faced with the need for long-term medications, which have variable efficacy and the potential for significant side effects. The use of corticosteroids and narcotic analgesics in particular has been shown to be associated with a higher risk of serious infection and poor outcomes.² Specialists struggle in order to ensure that long-term effective therapy is received by all patients. Patients' QoL can be impaired, especially during disease flares, which can include bloody diarrhoea, fever, weight loss and abdominal discomfort.³ This can be taxing to the patient from a psychological and physical standpoint.

A patient's level of compliance/adherence to treatment is an important factor in almost all chronic illnesses. Due to the incurable nature of IBD, consistent and indefinite therapy is necessary in order to maintain remission of the disease.⁴ Psychological factors, including depression and uncertainty in effectiveness, have been shown to be associated with non-adherence to prescribed medical regimes.⁵

A patient's understanding of this disease and the treatment being received may also influence adherence. Evidence suggests that when patients are educated about their IBD, compliance and anxiety levels tend to improve and presentations to the emergency department reduced.^{6,7} In order to achieve higher levels of understanding, information booklets and achieving a good therapeutic relationship may be necessary.

When patients are acutely unwell, the treating physician often focuses on the acute physical situation and thus, social and emotional issues are often not adequately addressed. The reasons for this include busy clinics where time can be restricted and thus opportunities are limited to assessing the patient's physical health and the medical practitioners' training focus which has been traditionally restricted to the acute care model. IBD patients with a poorer QoL and an inability to cope are more likely to deal with their issues via emotional discharge and support-seeking. It is these patients who potentially stand to benefit from psychological intervention.⁸

Multidisciplinary care is known to improve the management of some chronic diseases.⁹ However, there is little to no data on whether this approach is also beneficial for IBD patients. In 2007, a formal IBD service (IBDS) with dedicated medical/surgical, nursing and allied health staff within a multidisciplinary clinic focus was introduced at our institution, the Royal Adelaide Hospital (RAH). We therefore examined whether this more proactive model of care (as opposed to the standard previous acute reactive model) has lead to tangible improvements for our patients.

Methods

The RAH is the busiest hospital in South Australia and currently oversees the treatment of over 600 000 patients, including approximately 600 IBD patients.¹⁰ A formal IBDS was introduced in April 2008.¹¹ This consisted of a dedicated weekly IBD clinic and a joint medical-surgical clinic for IBD patients. The service was staffed by several experienced gastroenterologists, an IBD fellow and a trainee registrar. Whenever possible, patients were seen by the same doctor. There was also heavy involvement by a specialty IBD nurse, which included but was not limited to:

- 24 h access to the IBD nurse via telephone help-line;
- Proactive monitoring to help with medication compliance and dosage adjustment, and early detection of the drug's adverse effects and non-response;
- Management of clinic appointments according to the clinical need;

- Education and information leaflets for all new patients and those with treatment changes.

The IBDS also provided education to medical practitioners at clinical meetings, provided treatment guidelines and encouraged referral of patients to the service for review/advice.

In 2007, prior to the introduction of a formal IBDS, a clinical audit was done at the RAH.¹² At that point in time, not all IBD patients necessarily had specialist gastroenterology care with no access to the nurse support described previously, and no routine service to coordinate appointments between doctors, endoscopists and surgeons. In summary, all IBD patients with any encounter(s) with the RAH over a 6-month period (from November 2007 till March 2008) were identified. These patients were then asked to complete a detailed questionnaire. Responders to the initial audit (n=162) were asked to repeat the same questionnaire in 2009, ≥18 months after their initial survey (following introduction of the IBDS).

Data from the two surveys were compared, looking at disease knowledge (The Crohn's and Colitis Knowledge Score - CCKNOW), satisfaction with management, QoL (IBD-QOL), depression, anxiety (hospital anxiety and depression score), compliance (medication adherence rating scale) and medication use in the 12 months preceding each audit.¹³⁻¹⁶ These measures could only be compared between the two audit periods in patients responding to the surveys. However, inpatient healthcare use was determined for all 2007 responders by examining the hospital's central admission registry, and this enabled us to capture episodes of inpatient care for both responders and non-responders to the second (2009) audit, thus enabling us to quantify any 2009 'responder bias'. Comparisons were conducted with Fisher exact tests, binomial test (proportions), paired t-tests and Wilcoxon Ranks test (means) as appropriate.

The RAH Research Ethics Committee approved both audits. Return of a completed survey was regarded as consent.

Results

In the first audit period, 256 IBD patients were identified and 162 responded (response rate 63%). As previously reported, responders and non-responders did not differ substantially.¹² At follow-up in 2009, 81/162 (50%) again responded to the subsequent survey. Of these responders, 96% (78/81) used the service. Responders were older than non-responders (median 54.4 vs 38.2 years, $p<0.001$) but otherwise groups did not significantly differ in terms of gender, IBD subtype, disease duration, healthcare use and psychological comorbidity (all $p>0.20$). Of the 81 responders, median disease duration was 7 years, 61% had Crohn's disease (CD), 52% were women figure 1.

Figure 1 In the first audit period, 162 of 256 patients responded. In 2009, 81 again responded to the repeat survey. Of the 81 'repeat responders', 49 had CD and 30 had ulcerative colitis (UC).

Figure 2 A reduction in total hospital admissions was seen in 2009 following the introduction of a formal IBDs.

Inpatient healthcare use

Among the 2009 responders ($n=81$), hospitalisation fell from 65 admissions (in 39 subjects) to 42 admissions (in 24 subjects). This represents a significant decrease in both the mean numbers of admissions per patient (0.80 vs 0.52 ; $p=0.024$) and the proportion of patients requiring admission (48% vs 30% ; $p=0.014$). When examining CD and UC admissions separately, a benefit is seen regardless of the disease process (CD admissions 40 vs 30 ; UC 25 vs 12), making this unlikely to be due to newly available antitumour necrosis factor (anti-TNF) therapy, as funded access to anti-TNF therapy in Australia is restricted to CD. Nor are these effects likely to be due to responder bias as significantly decreased hospital admissions were also seen in the 2009 non-responders ($n=81$) (CD 77 vs 17 admissions, or proportion admitted: 62% vs 19% $p<0.0001$ and UC 25 vs eight admissions, or proportion admitted 32% vs 17% $p=0.26$) figures 2–5.

Medication use

Fewer patients reported the need for a course of steroids the following year ($37/81$ vs $27/81$; $p=0.018$). Pleasingly, the number of patients using opiates in the year preceding survey 2 was statistically significantly reduced compared with survey 1 ($24/81$ vs $12/81$;

$p=0.037$). Overall medication use was also statistically significantly reduced with 2009 responders reporting on average 4.65 medications per patient as compared with 5.63 in 2007 ($p<0.05$) figure 6.

Ancillary measures

The Short Inflammatory Bowel Disease Questionnaire (SIBDQ) score (out of 70) showed a slight increase (mean 46.37 vs 49.8 $p=0.053$) with a score of 5 being the minimum clinically relevant change in score. In addition, compared with baseline, the proportions of patients with improved knowledge, adherence, satisfaction with care, anxiety and depression scores were 63% (95% CI 51 to 73), 62% (95% CI 50 to 72), 65% (95% CI 54 to 76), 52 (95% CI 40 to 63), 43 (95% CI 32 to 55), respectively.

Discussion

Various studies have called for better quality and consistency of care for IBD patients, including Casellas *et al* who highlighted deficiencies in patient education and healthcare accessibility, while Stone *et al* pointed out the need for increased and likely positive impact of specialist input in these patients.^{17 18} However, few data are published to date attesting to the effectiveness (or otherwise) of these recommended interventions. In this prospective cohort study, we have now

Figure 3 In 2007, 48% of the patients required inpatient hospital care.

Figure 5 A lower proportion of 2009 non-responders required hospital admission, suggesting a 'cohort' rather than 'responder specific' effect.

Figure 4 In 2009, a significant reduction in the proportion of patients requiring hospital admissions was demonstrated.

Figure 6 In 2009, fewer patients used corticosteroids and opiates.

demonstrated that the introduction of an IBDS at our centre (RAH) is associated with broad, multifaceted improvements in patient outcomes. Most importantly, we have demonstrated tangible significant reductions in known negative markers of IBD morbidity³ including hospital admissions, polypharmacy, steroid and opiate use. Moreover, the reduction in hospitalisations is seen equally in non-responders, demonstrating a lack of responder bias. General trends of improvements in QoL, adherence, patient satisfaction and psychological comorbidity scores were also seen. However, the clinical relevance of these gains is yet to be ascertained.

Mawdsley *et al* showed that a specialised IBD clinic provided better care (defined by meeting certain criteria) when compared with general gastroenterology clinics.¹⁹ Unlike Mawdsley *et al*, our study focused on actual patient outcomes such as hospitalisation and steroid use rather than the care delivered meeting certain criteria. It is reassuring that both these assessment approaches are consistent in supporting benefits from more focused IBD-specific care. This congruence between these two studies using different approaches and performed in different healthcare settings, makes it highly likely that the benefits are real, clinically relevant and related to the intervention.

A recent Canadian retrospective study of over 3000 patients with CD diagnosed between 1988 and 2008 has shown that specialist gastroenterologist involvement was associated with a reduced rate of resection surgery.²⁰ They propose that this reduced need for resection is a surrogate measure for an improved clinical outcome with specialist care. Although our audit encompasses a smaller number of patients, our centre has used a multidisciplinary IBDS as the intervention, and showed a faster improvement in outcomes, with a greater level of clinical detail being available for assessment.

Possible limitations of our study include the relatively short time-frame between surveys—15 months, which is a relatively short term for a chronic disease with the potential need for lifelong medications and follow-up. A longer duration between surveys may have allowed more accurate assessment of any relevant changes in depression and anxiety scores. It may also have allowed a larger improvement in IBD knowledge. However, even without longer follow-up, reduced admissions, polypharmacy, steroids and opiate use are noted, indicating that gains can be made independently of knowledge and large improvements

What is already known on this subject?

- ▶ The incidence of IBD varies between 37 to 246 cases per 100 000 for UC and 26 to 199 per 100 000 for CD depending on the region of the world.
- ▶ Multi-disciplinary care is known to improve outcome in some chronic diseases.
- ▶ Little data has been published to date, to attest to the effectiveness of specialist input, patient education and increased healthcare accessibility in IBD patients.

What are the new findings?

The introduction of a formal IBD service, with dedicated medical/surgical, nursing and allied health staff has had a positive impact on IBD patient care.

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

This study may encourage other major healthcare facilities to adopt a similar proactive approach to the management of IBD patients.

in psychological status. Longer follow-up may have indeed increased the gains. Another drawback is that patient questionnaire responses and their treatment were not verified. However, all inpatient healthcare use is verified and consistent with the self-report data being true. Furthermore, there was a lack of contemporaneous controls in our study as all patients had access to the IBDS as it was not felt to be ethical or practical to randomly include or exclude subjects.

Given our data and that of others, we now recommend that other major healthcare facilities adopt a similar proactive approach to the management of IBD patients, as this model of care appears better placed to deliver than the single-patient, single-doctor mode.^{19 20} Moreover, now that these clinical and financial benefits have been shown, it appears unjustified to withhold them from patients in order to perform a randomised trial.¹¹

Conclusion

The introduction of a formal IBDS at the RAH appears to have had a positive effect on IBD patient care, especially with regard to reduced hospital admissions, poly-pharmacy, and glucocorticoid and opiate use. Simple measures implemented by the specialised IBD nurse and other support staff enhance patient outcomes in IBD care and result in significant decreases in inpatient care. Despite increased costs in additional staff to run a dedicated service, these measures are thus likely to be cost effective.

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Competing interests None.

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