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Crohn's & Colitis Australia inflammatory bowel disease audit: measuring the quality of care in Australia

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Introduction

Crohn's disease and ulcerative colitis are life-long gastrointestinal disorders that commonly present in adolescence and early adulthood[1]. Collectively known as inflammatory bowel disease (IBD), the conditions are an established global problem,[2] and Australia has among the highest prevalence in the world. It is estimated that between 74,000 and 91,000 Australians live with IBD.[3]

IBD affects gut function and causes bowel-related symptoms beyond the usual imposts of feeling unwell, and creates particular nutritional and psychosocial problems which necessitate specialist dietetic and psychological input. Many of the therapies are complex, making safety monitoring and specialist pharmacy input necessary – hence the real need for true multidisciplinary care, beyond medical specialists and extended nursing roles.

In 2012 Crohn's & Colitis Australia (CCA) commissioned PricewaterhouseCoopers (PwC) to assess IBD service models in Australia. The PwC report[3] identified two important problems: increased costs of healthcare utilisation and variability in the quality of care. The 2012 hospital costs attributable to IBD were estimated to be in the

order of $100 million. Productivity losses totalled more than $361 million and other economic costs were valued at over $2.7 billion for the year.

Quality of care implies consistent delivery of evidence-based care to all patients. Decreasing variability will lead to better individual outcomes, a healthier population and reduced costs.[4] The PwC report detailed problems of inconsistent access to care, support and education across Australia, and while acknowledging pockets of excellence in dedicated IBD services, found that even those hospitals were hampered by disparate and insecure funding.

To address these issues, CCA developed a set of national IBD multidisciplinary standards of care (the Australian IBD Standards) against which care could be audited.[5] For ease of access and because inpatient care is one of the most expensive components in IBD care, we chose initially to audit IBD care within public hospitals. The main components of the national inflammatory bowel disease audit, known as the IBD Audit were: structural (organisational survey), e.g. physical facilities, equipment and human resources; process, e.g. diagnosis, treatment, preventive care, and patient education obtained from medical records; and outcomes measured, wherever possible, by changes to health status, or healthcare utilisation.

The aims of this paper are to:

1. Describe the organisation, services and resources available to hospital patients with IBD,
2. Assess hospital adherence to the Australian IBD Standards, and
3. Compare quality of care between hospitals with and without an IBD service.

Methods

The IBD Audit was based on the United Kingdom IBD Audit undertaken by the Royal College of Physicians.[6] Hospitals were invited to complete:

1. An organisational survey - a one-off survey focused on the activity, organisation and resourcing of IBD services at their hospital.
2. Clinical audits - of IBD inpatient care records against selected standards in the Australian IBD Standards in participating hospitals.

The IBD Audit tools are shown in appendix 1 & 2 (organisational and clinical respectively).

Sites for the organisational survey and clinical audits

138 hospitals identified from the Australian Institute of Health and Welfare (AIHW) public hospital listing 2012-2013[7] were invited to participate in the IBD Audit. Invitees included all public hospitals in major cities or inner regional areas with more than 100 beds and outer regional or remote hospitals with more than 50 beds.

Patient sample

Only inpatient episodes at participating hospitals were audited. Cases were selected based on IBD being the main reason for admission and an admission date between 1 December 2013 and 30 November 2014. Consecutive admissions were audited, with 20-50 cases per site audited according to a scale based on hospital bed numbers, e.g. 20 audited for a 50-bed hospital and 50 for a 500-bed hospital.

Cases were identified by coding searches. Inclusion criteria required the case to be admitted, have acute care, be a multiday stay and have a principal diagnosis (ICD-10 AM codes) of:

- Crohn's disease (K50.0, K50.1, K50.8 and K50.9)

or

- Ulcerative colitis (K51.0, K51.2-K51.5, K51.8, K51.9 and K52.3)

Survey tools and IBD standards

The IBD Audit survey tools and Australian IBD Standards were developed and validated by the IBD Quality of Care Steering Committee (appendix 3) based on the UK IBD Audit. User acceptance testing was undertaken by the project staff and one hospital before audit launch.

Data collection

The organisational surveys were completed by hospital staff with knowledge of the processes involved in service delivery in 2014 to inpatients with IBD, such as gastroenterologists, department heads, IBD nurses and health-service managers. The clinical audits were completed by hospital staff with clinical auditing capability such as clinicians, or health information staff. Hospital data was submitted via a secure web-tool.

Data analysis

Descriptive statistics included mean (standard deviation), median, and the chi-squared and t-test for significance. All data were aggregated to provide national estimates and variables were summarised by type of hospital (general or paediatric), type of IBD condition (ulcerative colitis or Crohn's disease) and by defined Partial IBD Service.

Data were analysed using Stata Statistical Software: Release 12 (College Station, TX, USA: StataCorp LP, 2011) and Microsoft Excel 2013.

Results

Characteristics of participating hospitals

Of the 138 hospitals invited to participate in the IBD Audit, 83 (60%) registered to participate, and 71 (51%) completed the organisational survey. There were six paediatric hospitals and 65 general hospitals. All States and Territories were represented except for the Northern Territory. Twenty-eight percent of hospitals had fewer than 200 beds (19/69), 35% had between 200-399 beds (24/69) and 38% had more than 400 beds (26/69). Fifty one (72%) were located in a major city. Of the 71 who completed the organisational survey, 52 (73%) also completed the clinical audit.

Organisational survey

Staffing and resources available for patients with IBD were limited in hospitals around Australia (Table 1). Only one hospital had a full IBD team and so to enable some meaningful analysis of the possible value of a multidisciplinary IBD team, a Partial IBD Service was defined (at least a 0.4 full-time equivalent IBD nurse, a named clinical lead and an IBD helpline). Seventeen hospitals had a Partial IBD Service. The majority (>80%) had access to a stoma nurse or gastroenterologist. However, only two-thirds had access to a gastroenterologist with clinical focus on IBD or a colorectal surgeon. Only a third of hospitals had access to IBD nurse specialists or IBD clinical trial nurses.

There were significant differences in staffing and resources between paediatric hospitals and general, predominantly adult, hospitals (specified in Table 1). Paediatric hospitals were more likely to have an IBD helpline and, key treating staff on site (e.g. stoma nurse, gastroenterologist or IBD nurse specialist).

Important services and resources available for treating patients with IBD varied across hospitals (Table 2). Less than half the hospitals had multidisciplinary meetings where complex IBD cases were discussed. Only 28% of hospitals had a policy or protocol for the management of acute severe ulcerative colitis. Two-thirds of new patients were provided with written information about relevant patient organisations. Urgent

referrals were seen within 4 weeks or more rapidly if clinically necessary in the majority of hospitals (86%).

Clinical audit

Characteristics of audited patients

There were 1440 inpatient episodes audited (37 mean age, 51% female, 53% Crohn's Disease, 91% metropolitan hospital). Over 60% of patients were aged under 40 (903) and 10% were less than 18 years of age (144). The average length of stay was 7.5 days for Crohn's disease and 8.3 days for ulcerative colitis. See detail on patient characteristics in (Table 3).

These 1440 admissions represented 26% of all IBD admissions nationally (excluding ACT) as captured by AIHW for the same timeframe.

Sixty percent of patients (Crohn's disease: 464/767, 60 %, ulcerative colitis: 401/673, 59%) were admitted as emergencies because of active disease. Forty-six percent (350/767) of Crohn's admissions and 37% (248/673) of ulcerative colitis admissions had been admitted to the same hospital in the preceding 2 years and a quarter of those (25% [86/350] and 27% [67/248]) had an admission in the preceding month. Fifty-six percent of admissions for Crohn's disease (266/473) and 44% for ulcerative colitis (188/424) had IBD duration longer than 5 years (excluding newly diagnosed).

Anaemia was present in 32% (247/767) of Crohn's disease patients and 39% (262/670) of ulcerative colitis patients at admission. Even higher rates were seen in those less than 18 years of age admitted for Crohn's disease (36/75). Nearly half of the sample had other significant medical problems, the most common of which was a psychological condition (30% [104/346] Crohn's and 25% [77/307] ulcerative colitis).

More than one in five patients (22% [168/767]) admitted with Crohn's disease had surgery, generally for bowel obstruction (26% [44/168]), the drainage of an abscess (25% [42/168]), or failure of medical therapy (22% [37/168]). Similarly, over one in six patients (16% [107/671]) admitted for ulcerative colitis had surgery which was usually colectomy (47% [50/107]).

Most patients (80% [Crohn's disease 616/767, ulcerative colitis 537/673]) were discharged on ongoing treatment to improve symptoms or long-term maintenance medications with significant risks of side-effects. These agents included corticosteroids (Crohn's disease, 61% [455/746]; ulcerative colitis, 80% [513/638]), immunosuppressive drugs (58% [430/746], 47% [302/639]) and biological agents (26% [194/746], 16% [100/639]).

Quality of care

The clinical audit surveyed adherence to quality of care standards in the national Standards (Table 4) and identified deficiencies across all domains. Fundamental aspects of history (such as disease extent and severity), important aspects of the physical examination, and results of essential investigations were missing in the documentation (Table 5). Approximately two-thirds of patients were treated on a specialist gastroenterology ward. Less than half the patients were reviewed by a dietitian during admission and less than 20% were assessed by an IBD nurse. Body mass index was recorded in 40-45% of patients. Around half the patients had laparoscopic surgery, the accepted standard of care. Of those identified as having a probable comorbid mental health issue, less than a quarter received psychological support during admission, and of those, less than a fifth saw a psychologist.

Partial IBD Service quality of care

Hospitals that had some specialised multidisciplinary service, a Partial IBD Service, showed better performance against the Standards in a number of areas (Table 6). All Partial IBD Services were located in major cities while 63% of sites with no Partial

IBD Service were located in major cities. Age and gender were not significantly different between the two groups. Importantly, there was a 22% reduction in admission via emergency departments, better safety monitoring and more common provision of patient information.

The average length of stay was not significantly different between hospitals with and without a Partial IBD Service. However, hospitals with a Partial IBD Service had higher acuity patients as supported by the greater percentage of patients receiving infliximab for Crohn's disease (indirect evidence of greater acuity) which was approximately double at hospitals with an IBD nurse compared to hospitals without: estimated median 18% vs 10% per hospital (organisational survey).

Discussion

This first national survey of IBD services confirms that people living with IBD experience serious illness often requiring hospitalisation. These patients were generally young (60% were less than 40 years of age) and had significant medical comorbidity (a third were anaemic). Admission to hospital was most commonly for emergency treatment (60%), often on the background of chronic ill-health (over 40% of patients admitted had had an admission within the previous two years). Surgery was often necessary (22% Crohn's disease and 16% ulcerative colitis). The average length of stay was 7.5 days for Crohn's disease and 8.3 days for ulcerative colitis, which is longer than the national average for "all diagnoses" in 2013-14 (5.5 days).[7]

The Australian IBD Standards[5] outline the requirements for high-quality, integrated clinical care consistent with multidisciplinary chronic disease models of care. Only one of the audited hospitals had a full IBD service. Partial IBD Services were present in 24% of hospitals audited: this is overstating the national percentage because many hospitals declined to participate because of lack of resources. A telephone or email 'IBD helpline' was available at only 51% of hospitals.

The 71 participating hospitals provide a dataset that measures the performance of hospitals against the Standards. Hospitals that offered a Partial IBD Service demonstrated positive quality processes and outcomes. For example, reducing admissions through emergency departments has significant benefits for the patient as well as reduced demand on hospital resources.[8] Higher rates of safety monitoring has implications for medication-related complications. Patient information relating to the newly diagnosed, and relapse plans was more commonly provided by hospitals with a Partial IBD service. For ulcerative colitis patients, surgery was almost twice as likely to be performed laparoscopically at a Partial IBD service: 55% vs 29%. For many IBD-related surgical procedures, laparoscopic or laparoscopic-assisted surgery is the standard of care. [9-11] The positive outcomes associated with care at Partial IBD Services warrant further examination including adjustment for disease severity/treatment and demographic data in further research.

Despite the availability of evidence-based guidelines, few hospitals had protocols for IBD management in place. For example, only one in four hospitals had a protocol in place for the management of patients presenting with acute severe ulcerative colitis. IBD patients are at increased risk of thromboembolic disease,[12] and prophylaxis, unless contraindicated, is mandated during inpatient admission. Yet in this audit nearly a quarter of patient admissions did not receive appropriate prophylaxis. A plan for safety monitoring of those on immunosuppressive drugs or anti-TNF only existed for two-thirds of relevant cases. Nutritional risk screening occurred in fewer than 40% of admissions, despite the high prevalence of malnutrition in the IBD population.[13] Osteoporosis is common in IBD patients because of the use of steroids and the underlying disease process. Although 57% of hospitals had outpatient protocols for DEXA scans for patients on corticosteroids for more than 3 months, documentation of DEXA scans within five years was present in only 9% of patient records.

Mental health issues are common among people with IBD[14-16] and were the most common comorbidity in the sample (30% Crohn's disease; 25% ulcerative colitis), yet mental health clinicians were rarely part of the IBD team (4%).

Auditing of hospital care and other aspects of IBD care in the UK has led to improvements in quality of care.[6] By providing national and hospital-specific data on resources and delivery of care in Australia, the IBD Audit provides a baseline measure of IBD care in Australia. Planned future audits of IBD quality of care will focus on the patient experience of care and other areas not measured in this audit, such as private health care, outpatient care and use of biological treatments.

Limitations

This study was conducted as a voluntary quality improvement project and the sample may not be representative. The patient sampling bias was minimised by using a consecutive sample for a defined time period. Auditors collected information retrospectively from medical records introducing the risk of subjective interpretation and omission of events not recorded. Auditing bias was reduced by using data dictionaries, and help notes in the web survey tool. Patient inclusion and case identification relied on the ICD-10 AM codes applied by the hospital health information coders. The coding may be susceptible to differences in its application between coders. Comparison between the hospitals that had a Partial IBD Service and those that didn't was not adjusted for variables such as comorbidity, age and severity of disease socioeconomic status or other demographics.

Conclusion

This survey confirms that patients admitted to hospital suffering from IBD are young, chronically unwell, and are subject to substantial variations in clinical documentation and quality of care. It establishes a comprehensive baseline for future comparisons and highlights areas for improvement.

Only one hospital in this Australia-wide survey met accepted Standards for multidisciplinary care; hospitals with even a minimal multidisciplinary IBD service (IBD nurse, helpline and a clinical lead) demonstrated improved care in important areas.

Tables

Table 1 IBD hospital resources (as reported in Organisational survey)

Resources	Paediatric hospital n=6	General hospital n=65	Total N=71
IBD Team			
Full IBD team	0/6	1/65	1/71
Partial IBD Service	2/6	15/65	17/71
IBD Helpline (derived)	6/6	30/65	36/71
IBD service includes a mental health clinician	1/6	2/61	3/67
Key treating staff on site			
Stoma nurse	6/6	52/60	58/66
Gastroenterologist	6/6	46/59	52/65
Gastroenterologist with clinical focus on IBD	6/6	39/61	45/67
Colorectal surgeon	3/6	39/61	42/67
Access to a named ophthalmologist	3/6	5/61	8/67
IBD nurse specialist (excluding clinical trial nurses)	4/6	22/61	26/67
IBD nurse specialist has ongoing secure funding	2/6	19/61	21/67
IBD clinical trial nurse	2/6	21/61	23/67
Dietitian	6/6	29/61	35/67
Pathways for referrals			
Pathway for referring patients to a rheumatologist	4/6	24/60	28/66
Access to staff with special interest in gastroenterology			
Radiologist	4/6	23/61	27/67
Histopathologist	6/6	23/61	29/67
Named pharmacist	4/6	11/61	15/67

Table 2 Services and resources

	Total n/N
Multidisciplinary working	
Multidisciplinary meetings where complex IBD cases can be discussed	29/67
Medical/surgical joint or parallel outpatient clinics	16/66
Access to services	
Urgent referrals seen within 4 weeks	57/66
Enteral nutrition as a primary treatment (Crohn's disease)	42/67
Outpatient access to ultrasound, CT, MRI and endoscopic assessment within 4 weeks	51/67
Small bowel MRI (alternative to CT scans)	60/67
Policy or protocol for acute severe ulcerative colitis	19/67
DEXA offered if corticosteroids are used for more than 3 months	38/67
Hospital has a specific IBD clinic (outpatient)	34/67
Transitional care service within the hospital to support young people	16/66
Specialist review (face-to-face) for relapsed patients	42/64
Patient involvement and education	
Written information is made available to all new patients about relevant patient organisations	42/65
All newly diagnosed patients are given educational material routinely	50/65
Written information provided re accessing IBD services, follow-up arrangements	41/65
Written information for patients on whom to contact in the event of a relapse	43/65
Stable patients given a clear plan about what to do in the event of a flare-up	52/65
Patients are actively involved in management decisions about care	44/65
IBD patients are given the opportunity to provide feedback on their care	33/65
Practice and quality improvement	
Searchable database or registry of adult and paediatric IBD patients	26/65
IBD patients on both immunomodulator and biological therapy are regularly audited	10/66
Education opportunities focused on IBD for all medical and nursing staff	39/65
The IBD team provides IBD training for GPs on an ad hoc basis	23/65

Table 3: Characteristics of patients audited

Clinical Data	Crohn's disease n/N (%)	Ulcerative colitis n/N (%)
Female	419/767 (54.6)	321/673 (47.7)
Mean age (SD)	36 (16)	37 (19)
Age groups		
0-8	3/767 (0.4)	12/673 (1.8)
9-17	72/767 (9.4)	57/673 (8.5)
18-29	253/767 (33.0)	209/673 (31.1)
30-39	149/767 (19.4)	148/673 (22.0)
40-49	127/767 (16.6)	83/673 (12.3)
50-59	89/767 (11.6)	67/673 (10.0)
60-69	51/767 (6.7)	44/673 (6.5)
70+ years	23/767 (3.0)	53/673 (7.9)
Source of admission		
• Emergency department	520/767 (67.8)	434/673 (64.5)
• Referred by GP	39/767 (5.1)	36/673 (5.3)
• Advised to attend by IBD nurse helpline	16/767 (2.1)	17/673 (2.5)
• Referred in from hospital outpatient department	90/767 (11.7)	66/673 (9.8)
• Referred in from gastroenterologist rooms	54/767 (7.0)	70/673 (10.4)
• Referred in from surgical specialist rooms	35/767 (4.6)	34/673 (5.1)
• Transfer from another site	52/767 (6.8)	48/673 (7.1)
• Other	31/767 (4.0)	26/673 (3.9)
Current Smoker	201/767 (26.2)	50/670 (7.5)

Q1: Quartile 1; Q3: Quartile 3; SD: Standard deviation

Table 4: Processes of care for patients with IBD

	Crohn's disease n/N (%)	Ulcerative colitis n/N (%)
Assessment		
IBD nurse specialist consult	119/767 (15.5)	119/671 (17.7)
Formal nutritional risk assessment	305/767 (39.8)	254/670 (37.9)
Dietary therapy recorded as a treatment at admission	3/487 (0.6)	7/476 (1.5)
Consult with dietitian	337/767 (43.9)	282/670 (42.1)
Management		
Treatment on a specialist gastroenterology ward	473/767 (61.7)	427/671 (63.6)
Prophylaxis for deep venous thrombosis and pulmonary embolism given	554/767 (72.2)	515/670 (76.9)
Psychological support	85/767 (11.1)	74/671 (11.0)
Psychological and behavioural factors identified that contribute to poor disease management	63/746 (8.4)	37/639 (5.8)
Laparoscopic/laparoscopically assisted surgery	80/168 (47.6)	49/106 (46.2)
On immunosuppressive drugs on discharge	430/746 (57.6)	302/639 (47.3)
Plan for maintenance anti-TNF on discharge	194/746 (26.0)	100/639 (15.6)
DEXA scan completed (within 5 years)	11/122 (9.0)	10/113 (8.8)
In the 12 months prior to admission, the patient was taking oral steroids for Crohn's disease (at any time) for more than 3 months	122/767 (15.9)	113/670 (16.9)
• Appropriate dose reduction planned	84/122 (68.9)	77/113 (68.1)
Follow up planning		
Plan for safety monitoring of immunosuppressive drugs	288/430 (67.0)	192/302 (63.6)
Plan for safety monitoring of anti-TNF	135/194 (69.6)	76/100 (76.0)
Arrangements made for follow up by a dietitian	107/190 (56.3)	74/169 (43.8)
Outpatient psychological plan put in place	35/63 (55.6)	24/37 (64.9)

Table 5: Clinical documentation

	Crohn's disease n/N (%)	Ulcerative colitis n/N (%)
Extent of the disease recorded in admission notes	412/664 (62.0)	296/572 (51.7)
Paediatric Crohn's disease activity index (PCDAI) recorded at admission	4/69 (5.8)	-
Duration of disease stated in admission notes	473/664 (71.2)	424/572 (74.1)
Stool frequency documented	514/685 (75.0)	486/606 (80.2)
Presence of blood documented	447/712 (62.8)	425/612 (69.4)
Smoking status not documented	230/767 (30.0)	246/670 (36.7)
Weight recorded within 2 days of admission	458/767 (59.7)	421/670 (62.8)
BMI Recorded	310/767 (40.4)	299/670 (44.6)

Table 6: Comparison of Partial IBD Service and no Partial IBD Service

	Partial IBD Service n/N (%)	No Partial IBD Service n/N (%)	p-value*
Organisational survey all hospitals			
Combined medical and surgical outpatient reviews	10/17	6/49	<0.001
Regular multidisciplinary meetings to consider complex inpatient cases	15/17	14/50	<0.001
Access to clinical trials	15/17	15/48	<0.001
Searchable databases	14/17	12/48	<0.001
Routine provision of educational material to newly diagnosed people	16/17	34/48	0.05
Provision of written information about whom to contact in the event of a relapse	17/17	26/48	0.001
Clinical audit (18 years and over)			
Average length of stay	8.3	7.5	0.09^
Admissions via emergency department	335/576 (58.2)	535/720 (74.3)	<0.001
Plan for safety monitoring for biological agents in was implemented	109/122 (89.3))	78/132 (59.1	<0.001
Plan for safety monitoring for immunosuppressive drugs was implemented	231/292 (79.1)	197/358 (55.0)	<0.001
Ulcerative colitis patients laparoscopic surgery	29/53	12/42	0.03
Abdominal CT scanning adults with Crohn's disease	94/300 (31.3)	180/392 (45.9)	<0.001

*Chi-square test

^ t-test

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