Variation in Care of Inflammatory Bowel Diseases Patients in Crohn's and Colitis Foundation of America Partners: Role of Gastroenterologist Practice Setting in Disease Outcomes and Quality Process Measures

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Background: As variation in care has previously been linked to quality, we aimed to describe variations in inflammatory bowel diseases care by gastroenterology (GI) practice setting.

Methods: We performed a cross-sectional study within the Crohn's and Colitis Foundation of America Partners and used bivariate analyses to compare patient characteristics by GI practice setting (GI-academic [GIA], GI-private, or GI-other). Regression models were used to describe the effects of provider type on steroid use, disease activity, and the quality of life.

Results: The study included 12,083 patients with inflammatory bowel diseases (7576 with Crohn's disease [CD] and 4507 with ulcerative colitis [UC]). Nearly 95% reported visiting a GI provider annually. Also, CD patients seen by GIA were younger, better educated, used less 5-aminosalicylate agents, and had higher biologic and immunomodulator use ($P < 0.001$ for all). On multivariate analysis of CD patients, GIA used less steroids when compared with GI-private (odds ratio, 0.84; 95% confidence interval, 0.67–1.06) or GI-other (odds ratio, 0.66; 95% confidence interval, 0.49–0.89). GIA patients were more likely to be in remission, have flu vaccine, and have better quality of life. UC patients seen by GIA were younger, had more hospitalizations, and previous surgery ($P < 0.001$ for all). No differences existed for steroid use, remission, flu vaccine, or quality of life for UC care on bivariate or multivariate analyses.

Conclusions: Significant variations in care patterns and quality measures exist for CD across GI provider types, without similar variation in UC care. Interventions to reduce variations in care could improve the quality of care in CD.

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The art of medicine allows for some expected variation in practice; however, extreme variations in care have been used as markers of poor quality of care whether secondary to insufficient evidence, lack of knowledge, misuse of health care resources, or multiple equally effective approaches.[1,2] Such variation is evident in the care of both ulcerative colitis (UC) and Crohn's disease (CD) patients, although more prominent in the latter due to its heterogeneous nature.

Spiegel et al[2] showed that a wide variation in the everyday management of UC exists between community and expert gastroenterologists when presented with clinical vignettes. Similarly, significant variations in CD management were seen between community and expert gastroenterologists when provided with sample case vignettes,[3] especially with regards to the use of 5-aminosalicylate (5-ASA) medications. However, the response of a physician to a vignette may differ greatly from their management of actual patients.

Due to the variation in care evidenced in individuals with inflammatory bowel diseases (IBD), the American Gastroenterological Association developed an IBD performance measurement set with the intent of improving health outcomes through increased patient safety with an emphasis on preventive care and noncorticosteroid-based treatment options.[4] The Crohn's and Colitis Foundation of America (CCFA) also sponsored the publication of a set of quality indicators (QIs) in IBD management, including treatment, surveillance, and preventive care.[1] Use of

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such QIs establishes measurable benchmarks that can assess baseline quality of care and provide measurable standards for subsequent improvement in care.[5,6]

A focus on quality improvement and the development of evidence-based treatment guidelines has led to improved outcomes including decreased morbidity and mortality in other chronic diseases, such as cystic fibrosis.[7] Prior studies that have examined the differences in practice patterns of IBD care comparing community and expert gastroenterologists have been small in size and based on clinical vignettes. In our study, we aimed to use CCFA Partners to describe variations in medication use, remission rates, and quality of life measurements in individuals with UC and CD by gastroenterology (GI) practice setting.

METHODS

Crohn's and Colitis Foundation of America Partners

We used an Internet-based cohort, CCFA Partners, to describe variations in medication use, remission rates, and quality of life measurements by GI practice setting for individuals with self-reported IBD. CCFA Partners follows individuals with IBD who were recruited from CCFA e-mail lists and other social media outlets. Participants complete baseline and semiannual follow-up surveys regarding demographic, disease location and activity, medication use, prevention activities including vaccination and screenings, and quality of life measurements. Baseline characteristics of the population and further details of the cohort have been described elsewhere.[8]

Data Collection and Management

Data were collected in a Web-based format, and the interface performed range and consistency checks to improve data quality. The data management system has been previously described.[8] Special software was not required, and the Web forms were accessible from any computer running a modern Internet browser with an active Internet connection. Data on demographics, GI practice setting, disease type, IBD medications, remission, vaccination status, and quality of life were extracted from CCFA Partners core data. GI practice settings included GI-academic (GIA), GI-private (GIP), or GI-other (GIO; managed care or veteran's administration).

Study Design

We performed a cross-sectional study within CCFA Partners' Internet-based cohort including all individuals who completed a baseline survey, preventive health survey, and quality of life survey. We collected demographic data including age, gender, and education level. Factors associated with disease course, such as prior bowel surgery, hospitalization, and medication use, were also recorded. We assessed disease activity through validated self-report instruments including the short Crohn's disease activity index[9] for CD and the simple clinical colitis activity index[10] for UC. We used previously validated cutoffs for remission of <150 for short Crohn's disease activity index[9] and ≤ 2 for simple clinical colitis activity index.[11] We obtained data on quality of life through the short IBD questionnaire (SIBDQ).[12] We questioned participants about influenza vaccination, a QI endorsed by the American Gastroenterological Association.[13] We also collected data on smoking status, which is known to be associated with the course of both CD and UC.[14] Screening for smoking and recommendation for cessation intervention is a physician quality reporting system measure for IBD.

Statistical Analysis

Bivariate analyses were used to compare demographics, disease activity, and SIBDQ by GI practice setting. We used logistic and linear regression models controlling for factors associated with complicated disease course, including history of surgery, hospitalization, smoking, and disease duration, to determine the independent effects of provider type on outcomes such as steroid use, disease activity, and quality of life. We accounted for potential clustering using a robust variance estimator in the models. STATA 14.0 (College Station, TX) was used for all analyses. P values less than 0.05 were considered statistically significant. The Institutional Review Board at the University of North Carolina at Chapel Hill approved the study protocol.

RESULTS

Study Population

The study included 12,083 individuals with IBD who completed baseline demographic and preventive health surveys within CCFA Partners. Of those, 7576 reported having CD and 4507 reported having UC. Seventy-two percent of the study participants were women. The mean age of the study population was 42 years, and the mean time from diagnosis to study participation was 10 years. Nearly 95% reported visiting a GI provider at least annually. Of those consulting a GI provider, 73.8% saw GIP, 15.1% saw GIA, and 11.1% saw GIO. Additional demographic information is provided in Table 1.

Characteristics and Outcomes of CD Patients by Provider Type

CD patients seen by GIA were younger ($P < 0.001$), better educated ($P < 0.001$), used less 5-ASA agents ($P < 0.001$), and had higher use of anti–tumor necrosis factor (TNF) agents ($P < 0.001$), immunomodulators ($P < 0.001$), and combination therapy with immunomodulator and anti-TNF ($P < 0.001$) (Table 2). Those seen by GIA also had higher remission rates and flu vaccine rates with fewer current smokers. Although not statistically significant, GIA used narcotics in patients with CD at a lower rate (Table 2).

On multivariate analysis controlling for factors associated with a complicated disease course including surgery, hospitalizations, smoking status, and disease duration, GIA were less likely to use steroids for CD patients when compared with GIP

TABLE 1. Characteristics of the Population of Patients with CD and UC in CCFA Partners

Characteristic	IBD overall (N = 12,083)	CD (n = 7576)	UC (n = 4507)
Primary care physician (% yes)	90.2	90.2	90.1
GI provider (% yes)	94.6	95.2	93.7
GI provider type (of those with provider) (%)			
Academic	15.1	15.7	13.9
Private	73.8	73.2	74.8
Other[a]	11.1	11.1	11.3
Age, median (IQR), yr	42 (30–54)	42 (30–54)	42 (31–54)
Gender (% female)	72.1	73.0	70.7
Race (% white)	92.9	93.7	91.6
Education (% > high school)	91.0	90.2	92.4
Disease duration (IQR), yr	10 (4–21)	12 (5–23)	8 (3–17)
Prior hospitalization (% yes)	65.0	74.8	48.4
Prior surgery (% yes)	38.2	51.4	16.0
Medications (% current use)			
5-ASA	44.8	34.5	62.0
Biologic anti-TNF	32.1	40.4	18.2
Immunomodulator	25.6	28.5	20.8
Oral steroid	11.1	10.0	13.0
Narcotics	10.9	13.2	6.9
Remission (sCDAI <150 for CD and SCCAI ≤2 for UC; % yes)		58.3	42.4
SIBDQ, mean (SD)	4.8 (1.2)	4.7 (1.2)	4.8 (1.2)
Flu vaccine (% yes)	64.9	65.3	64.2
Current smoking (% yes)	7.7	10.1	3.8

[a]Other includes veteran's affairs, managed care, and other provider types.
IQR, interquartile range; SCCAI, simple clinical colitis activity index; sCDAI, short Crohn's disease activity index; SIBDQ, short inflammatory bowel diseases questionnaire.

(odds ratio [OR], 0.84; 95% confidence interval [CI], 0.67–1.06) or GIO (OR, 0.66; 95% CI, 0.49–0.89). The patients seen by GIA were also more likely to be in remission (OR, 1.18; 95% CI, 1.02–1.37 for GIA versus GIP and OR, 1.37; 95% CI, 1.11–1.68 respectively for GIA versus GIO), more likely to have flu vaccine (OR, 1.33; 95% CI, 1.15–1.53 for GIA versus GIP and OR, 1.53; 95% CI, 1.26–1.87 for GIA versus GIO), and more likely to have higher SIBDQ scores (beta coefficient, 0.17 and 0.25 respectively; $P < 0.001$ for both). Additional data are present in Table 3.

Characteristics and Outcomes of UC Patients by Provider Type

UC patients who were seen by GIA were younger ($P < 0.001$), had more prior hospitalizations ($P < 0.001$), and prior surgery ($P < 0.001$). UC patients treated at academic sites did use less 5-ASA ($P < 0.001$), more anti-TNF agents ($P = 0.003$), immunomodulators ($P = 0.001$), and combination therapy with anti-TNF and immunomodulator ($P = 0.001$). However, there were no differences in the use of steroids, remission rates, flu vaccine, or SIBDQ for UC care on bivariate (Table 4) or multivariate (Table 3) analyses.

DISCUSSION

An inverse relationship exists between variation in care and quality of care delivered to an individual.[3] In recent years, health care improvement efforts have focused on reducing unintended variation in care in an effort to improve patient outcomes and decrease costs and resource utilization. This is one of the first studies to describe variation in adult IBD care by GI practice setting. We found that significant variations in care patterns and quality measures exist for CD across GI provider types, without similar variation in UC care. We recognize that severity of disease is likely associated with important outcomes, such as steroid use or clinical remission; thus, we did control for factors associated with a prior complicated disease course. In our study, patients seen by GIA had increased risk of prior surgery, which may represent a more severe IBD phenotype. Despite this, a greater percentage of these complicated CD patients treated by GIA were in remission on biologic and immunomodulator therapy with less dependence on corticosteroids. GIA had a higher rate of influenza vaccination and also had fewer individuals who were current smokers within the CD population. It is possible that this provider group may place a greater emphasis on health care maintenance and preventive care. Important preventive health maintenance counseling in individuals with IBD includes yearly discussions about the importance of tobacco cessation and education about appropriate vaccinations for those with IBD. For example, yearly influenza vaccine is recommended in all patients with IBD, with avoidance of live virus vaccines in those on immunosuppression.[1]

Interestingly, there was less variation in care between GI practice settings within the UC population. There were minor differences in mediation utilization among UC provider types; however, overall rates of anti-TNF and immunomodulator use were much lower for each provider group in UC when compared with CD. Rates of steroid use and important outcomes, such as clinical remission and quality of life and preventive health measures (flu vaccine), did not differ among provider types for UC patients. Ananthakrishnan et al[15] recently described similar findings in a study population of IBD patients treated at 7 academic centers. The heterogeneous nature of CD as compared with UC may account for some of these variations in management. Management recommendations for CD patients differ substantially based on CD phenotype and location and other known risk factors for severe disease, such as young age at onset and smoking status. There is also more consensus in UC management, including greater expert agreement on a step-up medical

TABLE 2. Characteristics of Patients with CD Who Reported a GI Provider; by Type of Provider in CCFA Partners

Characteristic	Academic (n = 1120)	Private (n = 5215)	Other[a] (n = 788)	P[b]
Primary care physician (% yes)	88.7	91.6	90.7	<0.001
Age, median (IQR), yr	37 (27–50)	44 (32–55)	37 (26–51)	<0.001
Gender (% female)	72.6	73.2	73.6	0.87
Race (% white)	94.5	94.3	90.5	0.005
Education (% greater than high school)	93.9	90.3	87.1	<0.001
Disease duration (IQR), yr	11 (5–20)	12 (5–24)	11 (4–20)	<0.001
Prior hospitalization (% yes)	78.0	73.9	74.8	0.02
Prior surgery (% yes)	56.3	50.6	51.0	0.002
Medications (% current use)				
5-ASA	24.9	38.6	28.8	<0.001
Biologic anti-TNF	49.7	40.2	44.4	<0.001
IM	36.4	28.0	31.4	<0.001
Combination therapy (anti-TNF + IM)	17.6	11.1	13.6	<0.001
Oral steroid	8.7	10.2	12.4	0.03
Narcotics	12.1	13.1	15.4	0.11
Remission (sCDAI <150, % yes)	62.8	58.6	55.2	0.007
SIBDQ, mean (SD)	4.9 (1.2)	4.7 (1.2)	4.6 (1.2)	0.08
Flu vaccine (% yes)	71.6	65.4	62.3	<0.001
Current smoking (% yes)	6.6	10.5	9.7	<0.001

[a]Other includes veteran's affairs, managed care, and other provider types.
[b]Overall P by 1-way analysis of variance, Kruskal–Wallis, Pearson's chi-square as appropriate.
IQR, interquartile range; sCDAI, short Crohn's disease activity index; SIBDQ, short inflammatory bowel diseases questionnaire; IM, immunomodulator.

approach, the efficacy of medications such as 5-ASA, and the opportunity for a potentially curative surgery in the setting of severe disease.

The literature has previously shown differences in the care received in academic referral practices versus private practices. Reddy et al[16] recently examined care that IBD patients received before referral to a tertiary center and showed various deficits in care including underdosing of medications, prolonged use of corticosteroids, and failure to perform routine health care maintenance.[17] Similar improved outcomes at academic medical centers are seen in the literature of various other medical subspecialties. For example, Veenstra et al[18] described the delivery of higher valued care at academic centers leading to longer overall survival for those with stage IV colon cancer. In the cardiac literature, Patel et al[19] detailed greater adherence to established acute coronary syndrome guidelines in academic hospitals compared with nonacademic hospitals. A recent study also describes greater use of evidence-based acute and discharge therapies and

TABLE 3. Comparisons of Adjusted[a] Outcomes by GI Provider Setting Among Patients with CD and UC

	Steroid use	Remission	Flu Vaccine	SIBDQ[b]
	Adjusted OR (95% CI)	Adjusted OR (95% CI)	Adjusted OR (95% CI)	Beta Coefficient (95% CI), P
CD				
Academic versus private	0.84 (0.67–1.06)	1.18 (1.02–1.37)	1.33 (1.15–1.53)	0.17 (0.09 to 0.25); $P < 0.001$
Academic versus other	0.66 (0.49–0.89)	1.37 (1.11–1.68)	1.53 (1.26–1.87)	0.25 (0.14 to 0.36); $P < 0.001$
UC				
Academic versus private	1.07 (0.82–1.38)	1.02 (0.83–1.26)	1.14 (0.94–1.38)	−0.01 (−0.12 to 0.10); $P = 0.83$
Academic versus other	0.96 (0.68–1.37)	1.11 (0.84–1.47)	1.07 (0.82–1.39)	−0.03 (−0.19 to 0.12); $P = 0.68$

[a]Adjusted for surgery, hospitalization, smoking status, and disease duration.
[b]Short inflammatory bowel disease questionnaire.

TABLE 4. Characteristics of Patients With UC Who Reported a GI Provider; by Type of Provider in CCFA Partners

Characteristic	Academic (n = 582)	Private (n = 3125)	Other (n = 472)[a]	P[b]
Primary care physician (% yes)	88.8	90.6	93.2	0.01
Age, median (IQR), yr	37 (28–51)	43 (32–55)	36 (27–51)	<0.001
Gender (% female)	73.2	70.9	68.4	0.24
Race (% white)	91.2	92.1	89.5	<0.001
Education (% greater than high school)	93.8	93.0	89.6	0.02
Disease duration (IQR), yr	8 (3–14)	8 (3–17)	6 (3–14)	<0.001
Prior hospitalization	59.3	45.1	53.2	<0.001
Prior surgery (% yes)	21.8	12.9	16.5	<0.001
Medications (% current use)				
5-ASA	57.7	66.6	62.5	<0.001
Biologic anti-TNF	24.2	18.2	20.1	0.003
IM	28.0	21.0	21.6	0.001
Combination therapy (anti-TNF + IM)	8.9	5.3	4.2	0.001
Oral steroid	14.5	13.3	15.0	0.50
Narcotics	7.4	7.0	4.5	0.12
Remission (SCCAI ≤2), (% yes)	42.9	43.4	40.5	0.55
SIBDQ, mean (SD)	4.8 (1.3)	4.9 (1.2)	4.8 (1.2)	0.19
Flu vaccine (% yes)	66.7	63.6	65.3	0.32
Current smoking (% yes)	2.8	3.6	3.0	0.51

[a]Other includes veteran's affairs, managed care, and other provider types.
[b]Overall P by 1-way analysis of variance, Kruskal–Wallis, Pearson's chi-square as appropriate.
IQR, interquartile range; SCCAI, simple clinical colitis activity index; SIBDQ, short inflammatory bowel diseases questionnaire; IM, immunomodulator.

improved 30-day outcomes for those individuals presenting to an academic medical center with a non–ST-elevation myocardial infarction compared with a nonacademic medical center.[20]

There are numerous strengths to our study on variation in care in patients with IBD by GI practice setting. CCFA Partners includes a large and geographically diverse population. There is also diversity in provider type, whereas other studies have focused largely on academic centers. In addition, we measured actual care delivery and outcomes directly through patient report, an advantage over prior studies that used clinical vignettes to assess theoretical care patterns. We include important patient-reported outcomes such as SIBDQ that have not previously been measured in studies of variation in care in IBD. Prior studies have largely focused on treatment variations rather than on patient-reported outcomes.

We do acknowledge several limitations to our study. CCFA Partners is a volunteer sample of patients, thus may not be representative of general U.S. IBD population. Individuals with lower socioeconomic status, education level, and minority ethnic status may be underrepresented in this population due to the lack of Internet access and insufficient literacy to complete the online questionnaires. Unfortunately, this is a known limitation of Internet-based research.[21] It is also difficult to ascertain if variation in care between GIA and GIP is due to differences in provider or care center practices or due to differences in patient characteristics or preferences or both. Because CCFA Partners data are self-reported, there is also a potential for misclassification of disease status or type. However, the validity of self-reported IBD in CCFA Partners has been previously demonstrated.[21] Additionally, there may be an element of recall bias especially with regards to the rate of influenza vaccination. Prior studies have demonstrated that self-report likely overestimates true vaccination status.[22] We would argue that any misclassification in the case of vaccination is likely nondifferential because we do not expect an individual to fail to report receiving an influenza vaccination based on their provider type. Identification of provider type was also by patient report. Although misclassification is possible, this is also most likely to be nondifferential. Because this was a cross-sectional study design of baseline data, we do not have access to disease activity instruments preceding the outcome measures. However, we did control for disease duration, prior surgery, and prior hospitalization, all prior markers of a more complicated disease course.

As we continue to witness the expansion in treatment options available for both CD and UC, we must take action to reduce unintended variation in care. There has been great success in decreasing variation, improving care delivery, and thus outcomes in chronic diseases such as cystic fibrosis and pediatric IBD.[7,23,24] In both scenarios, quality improvement efforts aimed at better using previously available therapies and the function of the

health care delivery system resulted in significant outcome improvements for these individuals, with reduced variation in care. Although this is certainly promising, it may be more difficult to implement similar efforts in the adult population. For example, much of pediatric IBD care is centered at large academic centers compared with community practices, whereas adult IBD care is focused in the community.

CCFA is dedicated to quality improvement through the development of care pathway algorithms, QIs, and a more systematic and multidisciplinary approach to IBD care to ensure that all individuals with IBD are receiving optimal care regardless of GI provider type.[25] Our data show the existence of significant gaps in IBD care. Initial quality improvement efforts aimed at disseminating the available evidenced-based guidelines may result in improved patient care, a healthier IBD population, reduced health care costs, and less disconnect between the different GI provider types.[3,13] Collaboration between different provider types and redesigning elements of the chronic care delivery system will certainly be necessary to optimize the care of IBD patients.

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