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Inflamm Bowel Dis. Author manuscript; available in PMC 2014 March 01.

Published in final edited form as:
Inflamm Bowel Dis. 2013 March ; 19(3): 627–643. doi:10.1002/ibd.22986.

Systematic Review: The Role of Race and Socioeconomic Factors on IBD Healthcare Delivery and Effectiveness

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Abstract

Introduction—Race and socioeconomic status (SES) significantly affect the content and delivery of healthcare for multiple chronic disease states. Inflammatory bowel disease (IBD) is a set of complex, chronic diseases with the potential for significant morbidity if the content or delivery of healthcare is suboptimal. However, the literature related to race, SES, and IBD remains fragmented.

Methods—Using guidelines published by the Centre for Reviews and Dissemination, we performed a systematic review of the world's literature to identify studies related to: (1) IBD, (2) race/ethnicity, (3) SES, (4) healthcare delivery, and (5) healthcare effectiveness.

Results—We identified 40 studies that met inclusion criteria. Twenty-four studies (60%) assessed the role of SES, and 21 (53%) evaluated race. Topics addressed by these studies included: (1) Utilization of Medical and Surgical Therapy; (2) Adherence to Medical Therapy; (3) Clinical Outcomes; (4) Healthcare Access and Utilization; (5) Disease Perception and Knowledge; and (6) Employment/Insurance. We identified race- and SES-based disparities in the content of medical and surgical healthcare, utilization of inpatient and ambulatory medical care, adherence to medical therapy, and disease perceptions and knowledge. Several studies also identified race- and SES-based disparities in outcomes for IBD, including in-hospital mortality rates and health-related quality of life.

Discussion—Race- and SES-based disparities in the delivery and effectiveness of healthcare for patients with IBD exist in numerous domains, yet studies remain limited in their scope and breadth. Concerted, prospective, multicenter efforts are needed to address underlying causes for disparities and to identify methods of reducing and eliminating disparities.

Introduction

Inflammatory bowel disease (IBD) affects nearly 1.5 million adults in the United States and is a source of significant healthcare expenditure.[1,2] Previously thought to be a disease primarily of Caucasians and the affluent, IBD is increasingly common among non-white populations outside the United States.[3] Although population-based data describing IBD

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Disclosures: No conflicts of interest exist for any author.

Writing assistance: None.

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incidence in the United States are not available, trends in hospital utilization suggest that the burden of IBD among minority patients may be increasing.[4] The current economic climate in the United States may also result in increasing numbers of IBD patients lacking a regular source of healthcare coverage.

Minority race plays an important role in healthcare delivery and outcomes for numerous chronic disease states,[5] and there is significant interest in studying inflammatory bowel disease in the context of race. The supposition is that differences in outcomes between Caucasian and non-Caucasian individuals may give powerful insight into the genetic and environmental factors responsible for the disease. However, the role of race in IBD cannot be interpreted without understanding the contribution of highly linked socioeconomic factors that may also account for race-based differences in outcomes. The literature describing associations between race, socioeconomic status (SES), and IBD is fragmented.

To address this knowledge gap , we designed and performed a systematic review, summarizing studies within 6 key topic areas central to understanding the role of race and SES in IBD: 1) Medical and Surgical Therapy; 2) Adherence to Medical Therapy; 3) Clinical Outcomes; 4) Healthcare Access and Utilization; 5) Disease Perception and Knowledge; and 6) Employment and Insurance. Based on studies in other chronic disease states, we hypothesized that nonwhite race and factors associated with lower SES would be associated with reduced effectiveness and unequal delivery of healthcare services compared with patients in the ethnic majority (i.e., whites) and patients of higher SES.

Literature Search & Study Selection

We used the systematic review guidelines published by the Centre for Reviews and Dissemination as a guide for creating our systematic review protocol.[6] We initially searched the Medline database via PubMed on April 2, 2010 querying all included dates; we updated the search on December 7, 2011. Search strings included combinations of MeSH terms and keywords based upon five interwoven study concepts: (1) IBD, (2) race/ethnicity, (3) SES, (4) healthcare delivery, and (5) healthcare effectiveness. (Box 1 details the search strategy; available as supplemental material online). 752 article titles were screened for relevance; abstracts for articles appearing relevant were reviewed. Full articles were read in detail for 74 abstracts that appeared to meet inclusion criteria (Box 2, available as supplemental material online). The 36 studies that met inclusion criteria were included in our study. Reference lists from these articles were searched for additional relevant studies, producing four additional articles. Search of *Gastroenterology* supplements for abstracts presented at Digestive Disease Week from 2001 to 2010 that met inclusion criteria (other than having a full original article published in a peer-reviewed journal) produced two relevant abstracts that were included in the study.

Summary of Studies

Forty full articles and two abstracts were included in the review. Eighty-eight percent of studies were retrospective in design. The two most common data sources were individual clinics (36% of studies) and data collected for administrative purposes or through national surveys, such as the Nationwide Inpatient Sample (33% of studies). Seventy-six percent of studies included outpatients, and 31% included inpatients. Crohn's disease was more commonly studied (86% of studies) than ulcerative colitis (69% of studies). Twenty-six studies (62%) included SES as a variable of interest versus 21 (50%) for race. All studies of race included whites; 95% included African Americans, 33% included Hispanics, and 24% included Asians. Single- and multi-center studies had mean race-stratified sample sizes of 172 whites, 94 African Americans, and 32 Hispanics per study; only two studies included

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Asians. Mean race-stratified sample sizes for studies of data from national epidemiological databases were: 35,144 whites, 4,535 African Americans, 2,015 Hispanics, and 322 Asians per study.

Study Results & Interpretation

1) Utilization of Medical & Surgical Therapy

Table 1 summarizes the 10 studies of medical therapy utilization.[7,8,8-16] Seven of the nine studies comparing medical therapy across race groups identified race-based differences in medical therapy received by patients. In six of seven studies, whites were more often treated with immunomodulators and infliximab, suggesting disparities in access to, and/or utilization of, potentially disease-modifying therapy. Studies did not address reasons for these differences. When reported, disease severity was generally similar comparing African Americans and whites. Only one study found higher rates of infliximab use in minorities.[7] In this study of 245 newly diagnosed pediatric IBD patients, African Americans had more severe disease than whites, and were nearly twice as likely to receive infliximab (24% versus 13%, $P<0.05$). Two studies compared medication use between Hispanics and whites, but small sample sizes were small.[10,12] In the only study of SES, French researchers compared medical therapy received by socioeconomically deprived patients with Crohn's disease versus non-deprived patients.[15] The two groups had similar disease severity and were similarly likely to be treated with immunomodulators and infliximab.

Table 2 summarizes the twelve studies evaluating surgical therapy.[7,9,10,12,14,15,17-22] Three studies utilized the Nationwide Inpatient Sample, a large nationally representative database of hospitalizations.[19,21,23] Strengthened by larger sample sizes than single center studies, two of the three studies documented clear differences in surgical care by race. Among UC patients in the Nationwide Inpatient Sample from 1998 to 2003, minorities were significantly less likely than whites to undergo colectomy (African Americans 54% less likely and Hispanics 26% less likely). Among those undergoing surgery, race-based differences in type of anastamosis (ileostomy versus ileal pouch anal anastamosis) were not seen. SES, as assessed by type of healthcare coverage, was not associated with surgical therapy.[23] Among Crohn's disease patients in the Nationwide Inpatient Sample from 1998 to 2003, minorities were less likely than whites to undergo bowel resection (African Americans 32% less likely, Hispanics 30% less likely, and Asians 69% less likely). Furthermore, Medicaid healthcare coverage was associated with a 48% decreased likelihood of bowel resection.[19] Similarly, the French study of socioeconomic deprivation found 50% reduced likelihood of surgery among deprived patients.[15] Seven additional smaller studies evaluated IBD-related surgery by race. Three found that minorities underwent surgery less often than whites.[9,12,17] The other four studies did document numerical differences in surgical history favoring surgery among whites versus minorities, but small sample sizes limited the statistical significance of these differences.[7,10,14,20]

2) Adherence to Medical Therapy

Successful management of IBD usually includes regular the use of medications, some of which require frequent monitoring (i.e., immunomodulators), complex dosing regimens (i.e., steroid tapering), and/or administration outside the home (i.e., infliximab). Although race- and SES-based disparities in medication adherence exist for patients with other chronic diseases,[24] only five studies addressed this topic in IBD, and four of these identified race- and/or SES-based differences in medication adherence (table 3).[8,25-28] In the only race-based study to use a validated scale of medication adherence, African Americans had a 76% reduced odds of being adherent to medication use.[27] Patients' trust in the prescribing physician was positively correlated with adherence, as was older age. Another study found

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that African Americans were more likely than whites to discontinue medications due to perceived improvement, though the method for measuring adherence was not well-described.[8] Measures of SES studied, including employment status and marital status,[25,26] were also associated with adherence; type of healthcare coverage was not associated.[27] A more recent study of 1,663 French IBD patients found no association between SES and adherence to medical therapy.[28]

3) Health-Related Quality of Life & Other Clinical Outcomes

The most frequently studied clinical outcome was health-related quality of life (HRQOL), as evidenced by the seven studies identified (table 4).[29-35] Only one study evaluated race as an independent variable, finding no differences in HRQOL among African American versus white patients with Crohn's disease recruited from multiple clinics.[35] Among the other six studies evaluating SES and HRQOL, several variables were associated with higher HRQOL, including employed status,[29,31] higher income,[34] married status,[33] and higher educational level.[30,32]

Only four studies evaluated other clinical outcomes related to IBD (table 5).[19,23,36,37] Based on data from the Nationwide Inpatient Sample from 1998-2003, there were no race-based differences in in-hospital mortality rates for hospitalized patients with Crohn's disease or UC.[19,23] However, both studies identified associations between reduced SES and in-hospital mortality, despite multivariate analysis adjusted for multiple potential confounders. Among UC patients, the mortality rate was 3.3 times greater for Medicaid patients compared with privately insured patients.[23] For patients with Crohn's disease, income below the median was associated with a 29% increased risk of in-hospital mortality.[19] In the only study investigating disease flares, higher education was associated with an increased risk for initial, but not subsequent disease flares.[36]

4) Healthcare Access & Utilization

Studies have long shown inequalities in access to, and utilization of, healthcare services among patients of minority race and reduced SES.[38,39] Because IBD care often entails frequent visits to gastroenterologists, endoscopic examinations, and disease surveillance, equal access to, and utilization of, necessary services is of vital importance. Fourteen studies evaluated the impact of race and SES on healthcare access and utilization (table 6).[4,8,9,13,15,16,20,22,35,40-44] Three of four studies of race and ambulatory care found race-based differences, with discordant findings; all were single-center studies.[8,13,20,44] The largest study of 951 subjects found that African American men with Crohn's disease had 67% more ambulatory gastroenterology visits than white men with Crohn's disease; there were no race-based differences for women.[44] Two smaller studies found that African Americans with IBD had significantly lower rates of ambulatory gastroenterology utilization,[8,13] while the fourth study found no race-based differences.[20] These studies may reflect utilization, rather than access, as all subjects were seen in gastroenterology clinics at least once in order to be included in the studies. It is likely the presence or absence of race-based differences is center-dependent. No studies evaluated the role of SES in ambulatory gastroenterology access or utilization.

Seven studies evaluated access to, and utilization of, inpatient IBD care across race and SES. Based on data from the National Hospital Discharge Survey, rates of hospitalization for IBD appear to be increasing among multiple race groups.[4] Several studies suggested a modest association between nonwhite race and higher rates of hospitalization for IBD, but these studies tended to be small and not nationally representative.[9,16,35,41] African American subjects were 34% more likely to leave against medical advice in a study using the Nationwide Inpatient Sample.[40] However, SES appeared to be a stronger predictor of

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inpatient utilization than race, as patients with Medicaid healthcare coverage were 4.5 times more likely to leave against medical advice. In a different study of Nationwide Inpatient Sample data, uninsured subjects had an 80% reduced rate of elective hospitalization from 1999-2005 compared with privately insured patients, yet overall hospitalization rates among the uninsured increased three times more rapidly than insured patients, which may suggest lack of access to adequate ambulatory IBD care.[42] In a French study, socioeconomically deprived patients were more likely than non-deprived patients to require two or more hospitalizations for IBD.[15] In another intriguing (although small) study, underinsured subjects had a nearly 4-fold longer delay in diagnosis of IBD than insured subjects.[43]

5) Disease Perceptions & Knowledge

Patients' knowledge of, and perceptions regarding, IBD, likely affect their adherence to physicians' recommendations and disease-related outcomes. Three relatively small studies evaluated the role of SES and race in patients' knowledge and perceptions of IBD (table 7).[8,20,33] The two studies of race found that African American subjects had lower IBD-specific knowledge, and perceived greater intrusiveness of IBD on their lives compared with whites.[8,20] Hispanics also had lower disease knowledge than whites.[20] In the only study of SES, married subjects with UC perceived lower illness intrusiveness than unmarried subjects with UC.[33]

6) Employment & Insurance

The majority of studies related to occupation and insurance compared IBD patients with controls (table 8).[29,45-50] Universally, subjects with IBD reported higher rates of unemployment and use of sick leave than controls, and all but one study found higher rates of disability among IBD patients compared with controls. One study found that UC patients with active disease had higher unemployment rates compared with controls; UC patients with inactive disease had unemployment rates similar to controls.[47] Among UC subjects enrolled in a clinical trial, attaining remission was associated with a nearly 3-fold increase in regaining employment.[51] The one study of insurance found that Danish patients with IBD had 5-fold increased difficulty of obtaining health insurance and 87-fold increased difficulty obtaining life insurance compared with controls.[50] The only study of race identified significantly greater absence from work among African American Crohn's patients compared with white Crohn's patients.[35]

Conclusions

IBD is a chronic, costly, and {{}}morbid disease affecting nearly 1.5 million patients in the United States alone.[1,2] With disease incidence at its peak in the second and third decades of life, most patients can expect decades of potentially morbid disease, often requiring chronic, complex and costly therapy. IBD can be a challenging disease to successfully manage even among well-educated patients with excellent healthcare access, yet to this point, the literature describing relationships between race, SES, and IBD has been fragmented. Race and SES are associated with disparities in the content and delivery of healthcare for numerous chronic diseases,[5] and their role in IBD needs to be better understood.

In this systematic review of the world's literature, we identified 40 studies evaluating the role of race and SES in healthcare delivery and effectiveness among patients with IBD. This modest number of studies clearly identifies this as an understudied area within the IBD literature. Despite being relatively understudied, however, we found evidence for disparities in the effectiveness and delivery of healthcare among minorities and patients of reduced SES, confirming our hypothesis in several important areas.

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The most convincing evidence for disparities is for IBD-related surgery. Nationwide Inpatient Sample data reveal that minorities with UC are 25% to 50% less likely to undergo colectomy than whites, while minorities with Crohn's disease are 30% to 70% less likely to undergo bowel resection than whites.[19,23] Reasons for these differences are not clear. Do minority patients have less frequent surgical indications than their white counterparts? Are they less likely to be offered surgery? Are they more likely to decline surgery? One clue may lie in SES data, at least for Crohn's disease, where Medicaid health coverage was associated with a nearly 50% reduced odds of undergoing bowel resection.[19] Because there is no reason to assume that Medicaid patients would have less frequent indications for surgery than privately insured patients, this is highly suggestive of SES-related healthcare disparity, and minority patients were three times more likely than whites to have Medicaid coverage. The French study of socioeconomic deprivation also supports an association between reduced SES and lower surgery rates.[15] Of great concern is the significantly elevated mortality risk for hospitalized patients with reduced SES, despite analysis adjusted for multiple factors. Crohn's disease patients with median income below the average have a 29% increased in-hospital mortality,[19] while UC patients with Medicaid coverage have a 3.3-fold increased odds of in-hospital mortality (comparatively, Medicare patients have only a 1.8-fold increased risk, as might be expected given the older age of Medicare patients).[23] Race was not a predictor of mortality in either study. Among hospitalized IBD patients, it is clear that minority race and reduced SES are associated disparities in surgical care, and reduced SES is associated with increased mortality. These studies show both the power and the limitations associated with the use of national survey-based data, and they call attention to the need for dedicated, multicenter, prospective monitoring of IBD patient.

The presence of disparities in surgical care of hospitalized patients raises the question of disparities in medical care, because early, aggressive treatment of IBD may reduce the likelihood of future hospitalization and surgery. Unfortunately, studies of medical therapy are markedly limited due to lack of nationally representative ambulatory data. Nevertheless, seven of nine studies (largely single-center) identify race-based differences in medical therapy, and six of those seven found lower rates of potentially disease modifying drug use among minority patients.[7-13] These studies raise similar questions to those for surgical therapy: are minority subjects offered medications less often, do they accept them less often, or do they have reduced access to necessary medications? Or, are there intrinsic differences in IBD among patients of different races that lead them to receive different medications? Lacking any clear confirmatory evidence for generalizable race-based differences in IBD phenotype and course,[10,12,18] it is likely that race-based disparities are present. It is evident that stronger, more nationally representative data are needed describing ambulatory gastroenterological care for racially and socioeconomically diverse IBD patients. Although national surveys of ambulatory care exist (such as the National Ambulatory Medical Care Survey), relatively few subjects with IBD are included for each study year (based upon authors' personal investigation; data not shown).

While the forgoing studies suggest the presence of race- and SES-based disparities in healthcare for IBD, they leave many important issues unaddressed. These issues will likely remain obscure in the absence of collaborative, prospective multicenter efforts with the power to create protocols to address specific research questions. This has been done brilliantly in other chronic diseases such as cystic fibrosis, where the Cystic Fibrosis Foundation Patient Registry has followed the disease course of more than 25,000 patients for more than 40 years.[52] Similar efforts are also well underway in pediatric IBD, through the ImproveCareNow Network.[53] As of February 2011, the ImproveCareNow Network has enrolled 3,758 subjects at 29 sites, including more than 17,000 visits. 5,000 subjects are expected to be enrolled by the end of 2011 (personal communication with Dr. Wallace Crandall on, May 23, 2011). With disease prevalence even higher in adults than children,

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there is reason to suspect that similarly designed registries would have equal or greater power among adults. Such efforts would provide powerful and generalizable data of greater accuracy than current studies, and could enable researchers to answer specific questions related to race, SES, and IBD, among other topics.

Besides in-hospital mortality, hard outcomes among racially and socioeconomically diverse populations have been little studied. The best clinical outcomes to follow in IBD are unclear, given the significant heterogeneity in patient presentation and disease course. Possibly the most universally applicable outcome is HRQOL, an easily measurable and generalizable assessment of a patient's overall status, yet only one study evaluated associations between race and HRQOL.[35] Among studies of SES and HRQOL, most studied employment and education; only one evaluated income, and no studies assessed HRQOL based on access to regular source of gastroenterological care. Because race and SES are known to significantly affect HRQOL in other disease states,[54] HRQOL should be more thoroughly studied in IBD.

In addition to race- and SES-based disparities in IBD care, we found evidence for disparities in study participation/inclusion. While African Americans were included in 95% of race-related studies, Hispanics (33%) and Asians (24%) were studied much less frequently. Furthermore, average sample sizes for race groups differed significantly, sometimes by orders of magnitude. These limitations prevent drawing substantial conclusions regarding IBD in Hispanics and Asians. Furthermore, only seven studies evaluated infliximab use, and no studies evaluated other biologic agents, which are rapidly becoming first-line therapy for many patients with moderate to severe IBD. No studies evaluated the effectiveness of biologic therapy among racially diverse or socioeconomically deprived patients. Because patients seen in practice rarely match the demographics of subjects included in randomized, controlled trials, the utility of the biologic agents needs to be better understood among diverse patient populations. Thoughtful collaborative data collection as described above could begin to address these inadequacies.

There are several generalizations that can be drawn from our review. Firstly, it is evident that African Americans receive different surgical care, and probably different medical care, than whites. African Americans also appear to suffer disproportionately from IBD compared with whites, including greater difficulty affording healthcare, lower utilization of primary and gastroenterological care, higher rates of leaving the hospital against medical advice, greater impact of IBD on their occupations, and lower adherence to medical therapy, compared with whites.[8,20,27,35,40] Implementation science should seek to improve these disparities. Strong conclusions cannot be drawn regarding Hispanics or Asians, due to sample size limitations. As IBD is increasingly recognized in Asia and Latin America,[3,55] Asians and Hispanics with IBD must be better integrated into IBD-related research. Secondly, reduced SES is associated with different care among hospitalized IBD patients, including lower rates of bowel resections for Crohn's disease and increased in-hospital mortality.[19,23] Reasons underlying these disparities must be elucidated and addressed. Thirdly, available data are inadequate to characterize the effects of race and SES on IBD-related healthcare and outcomes. Few studies addressed both race and SES, and SES-related data were heterogeneous in the type of data collected. This is yet another area where prospective multicenter collaboratives would be powerful.

Finally, this review makes clear that future studies of race, SES, and IBD must be designed more thoughtfully and reported with greater transparency. Our understanding of the science underlying IBD pathogenesis and treatment continues to expand rapidly. While such research will remain a cornerstone of IBD care indefinitely, diminishing gains may be seen in population-level patient outcomes if healthcare systems fail to address the needs of the underserved, those of low SES, and minority patients. These needs would be better

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addressed by: 1) improved study design with transparency in reporting, 2) inclusion of minority and disadvantaged populations in IBD research, and 3) measuring, studying, and improving IBD care at the health systems level. In the studies identified in this review, many provided little or no description of methods for measuring SES and other variables, making it nearly impossible to compare studies or apply results to different IBD populations. We suggest that all studies of IBD (particularly those not fitting within the standard randomized controlled trial) should utilize the STROBE initiative guidelines, which detail what should be included in reporting of observational studies.[56] If journals publishing IBD research demanded adherence to these guidelines, the resulting studies would likely be of significantly greater value.

As the burden of IBD continues to increase among minorities in many parts of the world,[3,57] increased attention must be paid not only to epidemiology but to the availability and effectiveness of quality IBD care for disadvantaged populations. Healthcare barriers and disparities must be more clearly identified and their underpinnings understood. Implementation science should compare the effectiveness of different models of IBD care delivery in diverse settings, referencing other chronic diseases that are more sophisticated in terms of healthcare delivery. Studies of new therapies should specifically seek to enroll patients of lower SES and of nonwhite race/ethnicity, and results among such populations should be published. Benefits from such efforts would be numerous, including better generalizability of study results, improved understanding of IBD pathogenesis and course among diverse patients, and increased availability of cutting-edge therapies to patients who would otherwise be unable to access them. Furthermore, outreach to disadvantaged IBD populations should seek to educate and support patients to improve their HRQOL and correct disease misperceptions.

In summary, we identified disparities in the delivery and effectiveness of IBD-related healthcare for both minority patients and those of reduced SES. Concerted efforts are needed to better understand the reason for such disparities and to create interventions to improve healthcare for all patients with IBD.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

Grant support: Supported in part by a training grant from the National Institute of Diabetes and Digestive and Kidney Diseases (5T32DK007007-35), National Institutes of Health (JS).

Abbreviations used

CD	Crohn's disease
IBD	inflammatory bowel disease
QOL	quality of life
SES	socioeconomic status
UC	ulcerative colitis

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Table 1

Studies of medical therapy.

Study	Subjects	Setting	Outcomes studied	Race- or SES-based differences identified?	Relevant data
Eidelwein, 2007[7]	N=245 AA=58 W=187	Pediatric IBD inpatients at tertiary medical center	• Steroid use • Infliximab use • Immunomodulator use	Yes (race)	• AA had more severe disease than W • Infliximab used in 24% of AA; 13% of W • Steroids used in 90% of AA; 77% of W • No difference in use of immunomodulators
Jackson, 2008[8]	N=99 AA=55 W=44	CD inpatients and outpatients from three Atlanta hospitals	• Steroid use • Infliximab use • Immunomodulator use	Yes (race)	• AA had more fistulizing disease than W • Infliximab used in 11% of AA; 34% of W • No difference in use of immunomodulators or steroids
Moore, 2009[9]	N=245 AA=115 W=130	UC outpatients at tertiary medical center	• Use of any immunosuppressive medication	Yes (race)	• Disease severity not reported • AA 2.8 times less likely than W to receive immunosuppressive medications
Sewell, 2010[10]	N=228 A=51 AA=34 H=35 W=105	IBD outpatients at gastroenterology clinic for public hospital	• 5-ASA use • Steroid use • Infliximab use • Immunomodulator use	Yes (race)	• No difference in disease severity • Immunomodulators used in 9% of H; 34% of W • 5-ASA used in 77% of H; 92% of W • Steroids used in 34% of H; 60% of W • No differences in infliximab use
Flasar, 2008[11]	N=406 AA=102 W=304	IBD outpatients at several university-based clinics	• 5-ASA use • Steroid use • Infliximab use • Immunomodulator use	Yes (race)	• Steroids used in 56% of AA; 68% of W • Immunomodulators used in 28% of AA; 40% of W • Infliximab used in 10% of AA; 20% of W • No differences in 5-ASA use
Basu, 2005[12]	N=148 A=6 AA=54 H=30 W=58	IBD outpatients at single university-based clinic	• 5-ASA use • Steroid use • Infliximab use • Immunomodulator use	Yes (race)	• No differences in disease severity • No differences in 5-ASA and immunomodulator use for W versus H with UC • Steroids (for UC) used in 50% of W; 39% of H • No differences in steroid use for W versus AA with CD • Immunomodulators (for CD) used in 42% of W; 31% of AA • Infliximab (for CD) used in 22% of W; 14% of AA
Nguyen, 2010[13]	N=286 AA=137 W=149	IBD outpatients from single clinic	• Immunomodulator use • Infliximab use	Yes (race)	• AA with IBD less likely than W with IBD to use immunomodulators (52% versus 68%) • AA with CD less likely than W with CD to use infliximab (41% versus 60%)
Cross, 2006[14]	N=210 AA=55 W=155	CD outpatients at several university-based clinics	•Steroid use	No (race)	• No differences in disease severity

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Study	Subjects	Setting	Outcomes studied	Race- or SES-based differences identified?	Relevant data
					• Steroids used in 65% of AA; 75% of W
Santana, 2007[16]	N=65 W=21 Non-white=44	CD outpatients at university-based clinic in Brazil	• Steroid use • Immunosuppressant use	No (race)	• No differences in disease severity • Steroids used in 62% of W, 72% of nonwhites • Immunosuppressants used in 38% of W; 46% of nonwhites
Nahon, 2009[15]	N=207 “Deprived”=73 “Non-deprived”=134	CD outpatients and inpatients from six hospitals in Paris	• Recurrent steroid use • Infliximab use • “Immunosuppressive therapy”	No (SES)	• No differences in disease severity • Recurrent steroids used in 10% of deprived; 11% of non-deprived • Infliximab used in 18% of deprived; 13% of non-deprived • “Immunosuppressive therapy” used in 58% of deprived; 54% of non-deprived

5-ASA, 5-aminosalicylate; A, Asians; AA, African Americans; CD, Crohn's disease; H, Hispanics; IBD, inflammatory bowel disease; SES, socioeconomic status; UC, ulcerative colitis; W, whites

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Table 2

Studies of surgical therapy.

Study	Subjects	Setting	Outcomes studied	Race- or SES-based differences identified?	Relevant data
Nguyen, 2006[18]	N=23,389 AA=2,288 H=1,834 W=18,368 Other=899	UC inpatients included in NIS from 1998-2003	• Colectomy • Type of anastamosis	Yes (race) No (SES)	• AA 54% less likely than W to undergo colectomy • H 26% less likely than W to undergo colectomy • Permanent ileostomy in 47% of W; 38% of AA; 40% of H (P=NS) • J-pouch in 27% of W; 19% of AA; 24% of H (P=NS) • Medicaid coverage not associated with colectomy
Nguyen, 2007[19]	N=41,918 A=269 AA=4,760 W=34,388 Other=816	CD inpatients included in NIS from 1998-2003	• Bowel resection for CD	Yes (race) Yes (SES)	• AA 32% less likely than W to undergo bowel resection • H 30% less likely than W to undergo bowel resection • A 69% less likely than W to undergo bowel resection • Patients with Medicaid coverage 48% less likely to undergo bowel resection than privately insured patients
Moore, 2009[9]	N=245 AA=115 W=130	UC outpatients at tertiary medical center	• Colonic surgery	Yes (race)	• Disease severity not reported • AA 9.8 times less likely to have colonic surgery than W
Basu, 2005[12]	N=148 A=6 AA=54 H=30 W=58	IBD outpatients at single university-based clinic	• Bowel surgery	Yes (race)	• No differences in disease severity • 12% of H with UC had bowel surgery versus 37% of W with UC • No differences in surgery for CD in AA versus W
Deveaux, 2005[17]	N=178 AA=38 W=140	CD inpatients undergoing surgery at university hospital	• Type of bowel surgery	Yes (race)	• No differences in disease severity • Segmental colectomy in 24% of AA; 10% of W • No differences in frequency of small bowel resection, ileocolic resection, total proctocolectomy, abscess drainage
Nahon, 2009[15]	N=207 “Deprived”=73 “Not deprived”=134	CD outpatients and inpatients from six hospitals in Paris	• Intestinal resection or perianal surgery	Yes (SES)	• No differences in disease severity • 44% of “not deprived” subjects had surgery versus 22% of “deprived” subjects
Lesperance, 2009[21]	N=49,609 AA=2,941 H=1,075 W=31,146 Other=869	CD inpatients undergoing bowel resection included in NIS from 2000-04	• Type of bowel resection (laparoscopic versus open)	No (race)	• 6% of W and 6% of non-whites underwent laparoscopic surgery
Finlay, 2006[20]	N=148 AA=54 H=30 W=58	IBD outpatients at single university clinic	• Any surgery for IBD	No (race)	• Disease severity not reported • Any UC-related surgery in 7% of H; 25% of W(P=NS) • Any CD-related surgery in 35% of AA; 65% of W (P=NS)
Eidelwein, 2007[7]	N=245 AA=58 W=187	Pediatric IBD inpatients at tertiary medical center	• “Major surgical procedure”	No (race)	• AA had more severe disease than W

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Study	Subjects	Setting	Outcomes studied	Race- or SES-based differences identified?	Relevant data
					• 29% of W and 18% of AA underwent major surgical procedure (P=NS)
Cross, 2006[14]	N=210 AA=55 W=155	CD outpatients at several university-based clinics	• Any surgery for CD	No (race)	• No differences in disease severity • 42% of AA and 53% of W underwent CD-related surgery (P=NS)
Sewell, 2010[10]	N=228 A=51 AA=34 H=35 W=105	IBD outpatients at gastroenterology clinic for public hospital	• Any surgery for CD • Any surgery for UC	No (race)	• No differences in disease severity • 41% of W, 59% of AA, 30% of H, and 31% of A underwent surgery for CD (P=NS) • 12% of W, 13% of AA, 12% of H, and 13% of A underwent surgery for UC (P=NS)
Benchimol, 2011[22]	N=3,404 Low income=944 High income=1,286	Pediatric IBD patients enrolled in cohort based on administrative data	• Any surgery for CD • Any surgery for UC	Yes (SES)	• Low income children with Crohn's disease diagnosed after 2000 had 79% higher odds of intraabdominal surgery compared with high income children

A, Asians; AA, African Americans; CD, Crohn's disease; H, Hispanics; IBD, inflammatory bowel disease; NIS, Nationwide Inpatient Sample; UC, ulcerative colitis; W, whites

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Table 3

Adherence to medical therapy.

Study	Subjects	Setting	Outcomes studied	Race- or SES-based differences identified?	Relevant data
Jackson, 2008[8]	N=99 AA=55 W=44	CD inpatients and outpatients from three Atlanta hospitals	• "Compliance" with medical therapy, not further defined	Yes (race)	• 49% of AA compliant with medications compared with 77% of W • 27% of AA versus 9% of W discontinued medications because of perceived improvement
Nguyen, 2009[27]	N=235 AA=120 W=115	IBD outpatients from a single university-based clinic	• "Adherence" to medical therapy, using validated scale	Yes (race) No (SES)	• 50% of AA versus 80% of W adherent to medical therapy • 67% of privately insured subjects versus 54% of non-privately insured subjects adherent (P=NS)
Kane, 2001[25]	N=94	UC outpatients with quiescent disease at single university-based clinic	• "Adherence" to 5-ASA use, defined as consumption of >80% of prescribed medications over 6-month period	Yes (SES)	• Men twice as likely as women to be adherent • Married subjects 54% more likely than unmarried subjects to be adherent
Ediger, 2007[26]	N=304 Employed=203 Unemployed=101	Population-based IBD registry	• "Adherence" to medical therapy, using validated scale	Yes (SES)	• 7% of unemployed men and 34% of employed men were low adherers • 30% of unemployed women and 42% of employed women were low adherers (P=NS)
Nahon, 2011[28]	N=1,663 SES deprived=432 SES nondeprived=1,231	Questionnaire of French IBD patients	• "Adherence" to medical therapy, using validated scale	No (SES)	• Socioeconomically deprived patients had similar adherence to medical therapy as socioeconomically nondeprived patients

AA, African Americans; IBD, inflammatory bowel disease; SES, socioeconomic status; W, whites

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Table 4

Health-related quality of life.

Study	Subjects	Setting	Outcomes studied	Race- or SES-based differences identified?	Relevant data
Bernklev, 2006[29]	N=495 CD=161 UC=334	IBD outpatients in population-based prospective cohort in Norway	• HRQOL (using SF-36 and the Norway-IBDQ)	Yes (SES)	• Unemployment and disability status were associated with reduced HRQOL
Casellas, 2002[30]	N=354 CD=169 UC=185	IBD outpatients from a single university-based clinic in Spain	• HRQOL (using IBDQ)	Yes (SES)	• Higher education level associated with higher IBDQ score
Feagan, 2005[31]	N=573	CD outpatients enrolled in clinical trial	• HRQOL (using IBDQ and SF-36)	Yes (SES)	• Mean IBDQ score 121.8 for unemployed subjects versus 133.4 for employed subjects • Mean SF-36 physical health score 31.1 for unemployed subjects versus 36 for employed subjects • Mean SF-36 mental health score 37.4 for unemployed subjects versus 40.2 for employed subjects
Iglesias, 2009[32]	N=92	CD outpatients in remission enrolled in prospective cohort	• HRQOL (using SF-36)	Yes (SES)	• Lower education level associated with lower SF-36 score
Maunder, 2007[33]	N=155	UC outpatients recruited directly for study	• “Illness intrusiveness” via validated scale	Yes (SES)	• UC more intrusive among unmarried subjects versus married subjects
Rubin, 2004[34]	N=409	IBD outpatients in the United Kingdom	• HRQOL (using IBDQ)	Yes (SES)	• Subjects from lowest geographic income quintile had 9-point lower IBDQ score
Straus, 2000[35]	N=552 AA=145 W=407	CD outpatients recruited from multiple clinics	• HRQOL (SF-36)	No (race)	• No differences in disease severity • SF-36 score 56.3 in AA versus 61.1 in W, but P=NS in adjusted analysis

AA, African Americans; CD, Crohn's disease; HRQOL, health-related quality of life; IBD, inflammatory bowel disease; IBDQ, Inflammatory Bowel Disease Questionnaire; SF-36, Short Form-36 Health Survey; SES, socioeconomic status; UC, ulcerative colitis; W, white

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Table 5

Clinical outcomes.

Study	Subjects	Setting	Outcomes studied	Race- or SES-based differences identified?	Relevant data
Nguyen, 2006[23]	N=23,389 AA=2,288 H=1,834 W=18,368 Other=899	UC inpatients included in NIS from 1998-2003	• In-hospital mortality	Yes (SES) No (race)	• Odds of in-hospital mortality 3.3 times greater for Medicaid patients than privately insured patients • Crude in-hospital mortality was 0.91 per 1,000 hospital days among AA compared with 1.30 per 1,000 for W (P=NS)
Nguyen, 2007[19]	N=41,918 A=269 AA=4,760 W=34,388 Other=816	CD inpatients included in NIS from 1998-2003	• In-hospital mortality	Yes (SES) No (race)	• Income below the median associated with 29% increased risk of in-hospital mortality • Crude in-hospital mortality was 6.6 per 10,000 hospital days for W, 6.4 per 10,000 for AA, 9.7 per 10,000 for H (P=NS) • A had statistically lower in-hospital mortality (0 deaths) compared with other races
Hoie, 2007[36]	N=771	UC outpatients from multiple centers in Europe and Israel	• Disease relapse	Yes (SES)	• Overall 10-year relapse risk 67% • Higher education associated with 40% increased odds of first relapse • Educational status not associated with risk of subsequent relapse
Sentongo, 2002[37]	N=112 AA=9 W=101 Other=2	CD inpatients at single university hospital	• Vitamin D status	Yes (race)	• 56% of AA had hypovitaminosis D, compared with only 13% of W

A, Asians; AA, African Americans; CD, Crohn's disease; NIS, Nationwide Inpatient Sample; SES, socioeconomic status; UC, ulcerative colitis; W, whites

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Table 6

Healthcare access and utilization.

Study	Subjects	Setting	Outcomes studied	Race- or SES-based differences identified?	Relevant data
Jackson, 2008[8]	N=99 AA=55 W=44	CD inpatients and outpatients from three hospitals	• Ambulatory gastroenterology utilization • Ambulatory primary care utilization	Yes (race)	• AA had average 0.21 primary care visits per year compared with 1.31 per year for W • AA had average 2.3 gastroenterology visits per year compared with 3.2 per year for W
Nguyen, 2010[13]	N=286 AA=137 W=149	IBD outpatients from single clinic	• Ambulatory gastroenterology utilization • Barriers to care	Yes (race)	• AA less likely than W to see a gastroenterologist (0.43) or an “IBD specialist” (OR 0.37) regularly • AA had more concerns than W regarding costs of care (18% versus 7%) • AA had more difficulty than W obtaining referrals to specialists (12% versus 5%)
Veluswamy, 2010[44]	N=951 AA=340 W=611	IBD outpatients from single clinic	• Ambulatory gastroenterology utilization	Yes (race)	• AA males with CD had average 10 ambulatory gastroenterology visits per year versus 6 for W males • No race-based differences among UC patients or female CD patients
Finlay, 2006[20]	N=148 AA=54 H=30 W=58	IBD outpatients from single university-based clinic	• Ambulatory care (“routine checkups”)	No (race)	• 56% of W and 44% of AA with CD had “routine checkups” (P=NS) • 75% of W and 50% of H with UC had “routine checkups” (P=NS)
Benchimol, 2011[22]	N=3,404 Low income=944 High income=1,286	Pediatric IBD patients enrolled in cohort based on administrative data	• Hospitalization for IBD • Emergency department visits • IBD-related physician visits	Yes (SES)	• Low income children with IBD 17% more likely to be hospitalized, 21% more likely to visit emergency department than high income children with IBD • Low income children had 3.7 times more ambulatory physician visits than high income children
Kurata, 1992[41]	N=909 (Race-specific N not stated in manuscript)	CD outpatients from Kaiser Southern California 1987-88	• Hospitalization for IBD	Yes (race)	• AA and W more likely to be hospitalized (10.2 hospitalizations per 100,000 subjects for both groups) than A (2.0 per 100,000) or H (0.6 per 100,000)
Moore, 2009[9]	N=245 AA=115 W=130	UC outpatients at tertiary medical center	• Hospitalization for IBD	Yes (race)	• AA had 40% increased odds of hospital admission compared with W
Straus, 2000[35]	N=552 AA=145 W=407	CD outpatients recruited from multiple clinics	• Hospitalization for IBD	Yes (race)	• AA hospitalized mean 35.8 days per year versus 25.3 days for W
Kaplan, 2009[40]	N=93,678 A=374 AA=8,150 H=3,466 W=56,675 Other=25,012	IBD inpatients from NIS, 1995-2005	• Leaving hospital AMA	Yes (race) Yes (SES)	• 1.2% of W left AMA compared with 2.3% of AA (OR 1.34, CI 1.09-1.64) • No difference in AMA rates comparing W with A or H • 0.7% of patients with private insurance left AMA compared

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Study	Subjects	Setting	Outcomes studied	Race- or SES-based differences identified?	Relevant data
					with 3.2 of Medicaid patients (OR 4.55, CI 3.81-5.43) and 3.6% of uninsured patients (OR 4.53, CI 3.75-5.48)
Nahon, 2009[15]	N=207 "Deprived"=73 "Non-deprived"=134	CD outpatients and inpatients from six hospitals in Paris	• Hospitalization for IBD	Yes (SES)	• 56% of deprived subjects required two or more hospitalizations compared with 40% of non-deprived subjects
Nguyen, 2009[42]	Not reported	IBD inpatients included in the NIS, 1999-2005	• Hospitalization for IBD	Yes (SES)	• 59% reduced rates of any hospitalization for uninsured subjects compared with privately insured subjects • 80% reduced rates of elective hospitalization for uninsured subjects compared with privately insured subjects • Over study period, hospitalization rates increased by 64% among uninsured but only 21% among privately insured
Spivak, 1995[43]	N=40 Insured=20 Underinsured=20	IBD outpatients from single clinic	• Time from onset of symptoms to IBD diagnosis	Yes (SES)	• Mean delay in diagnosis 10.3 months for underinsured subjects versus 2.7 months for insured subjects
Santana, 2007[16]	N=65 W=21 Non-white=44	CD outpatients at university-based clinic in Brazil	• Hospitalization for IBD	No (race)	• 14.3% of W and 36.4% of non-W hospitalized for IBD within prior year (P=0.07)
Sewell, 2010[10]	Not reported	IBD inpatients from NHDS, 1994-2006	• Hospitalization for IBD	N/A	• Proportion of hospitalizations with discharge diagnosis of IBD increased significantly among W, AA, and A (race-specific figures not reported)

A, Asians; AA, African Americans; AMA, against medical advice; CD, Crohn's disease; CI, 95% confidence interval; H, Hispanics; IBD, inflammatory bowel disease; NHDS, National Hospital Discharge Survey; NIS, Nationwide Inpatient Sample; OR, odds ratio; SES, socioeconomic status; UC, ulcerative colitis; W, whites

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Table 7

Disease perceptions and knowledge.

Study	Subjects	Setting	Outcomes studied	Race- or SES-based differences identified?	Relevant data
Finlay, 2006[20]	N=148 AA=54 H=30 W=58	IBD outpatients from single university-based clinic	• Accurate understanding of IBD • Perception of disease limiting career choices	Yes (race)	• 31% of AA versus 8% of W with CD thought disease caused by allergies • 66% of AA versus 25% of W with CD thought disease caused by infections • 60% of AA versus 52% of W with CD thought that CD limits career choices • 70% of H versus 37% of W with UC thought disease caused by stress • No differences in career perceptions among H versus W with UC (specific data not reported)
Jackson, 2008[8]	N=99 AA=55 W=44	CD inpatients and outpatients from three hospitals	• Perceptions of disease control	Yes (race)	• 58% of AA versus 71% of W felt their disease was under control, despite similar objective level of disease control
Maunder, 2007[33]	N=155	UC outpatients recruited directly for study	• “Illness intrusiveness” via validated scale	Yes (SES)	• UC more intrusive among unmarried subjects versus married subjects

AA, African Americans; CD, Crohn's disease; H, Hispanics; IBD, inflammatory bowel disease; UC, ulcerative colitis; SES, socioeconomic status; W, whites

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Table 8

Occupation and insurance.

Study	Subjects	Setting	Outcomes studied	Differences identified?	Relevant data
Bernklev, 2006[29]	N=495 CD=161 UC=334 Controls: not stated	IBD outpatients enrolled in prospective cohort compared with age-matched controls (Norway)	• Employment status • Disability • Sick leave	Yes (IBD versus controls)	• Higher age-specific rates of disability (specific figures not reported) among IBD patients versus controls • Higher rates of sick leave (specific figures not reported) among IBD patients versus controls • 12% unemployment among IBD patients versus 4% among controls
Bernstein, 2001[45]	N=2,474 CD=1,232 UC=1,242 Controls=14,177	IBD outpatients from university clinic	• Employment status • Disability	Yes (IBD versus controls)	• 11% unemployment among male IBD patients versus 4% among male controls • 12% unemployment among female IBD patients versus 3% among female controls • 1.3% of IBD male patients disabled versus 3.6% of male controls • 1.3% of IBD female patients disabled versus 4.6% of female controls
Boonen, 2002[46]	N=680 CD=282 UC=359 IC=39 Controls=715	IBD outpatients in IBD registry compared with controls (Netherlands)	• Employment status • Disability • Sick leave	Yes (IBD versus controls)	• Males with IBD 11% less likely to be employed than male controls • Females with IBD 6% less likely to be employed than female controls • IBD patients 2.6 times more likely to receive disability compared with controls • IBD patients took more sick leave days (mean 19.2 per year) than control subjects (mean 11.8 days per year)
Longobardi, 2003[48]	N=187 (cases) Controls=10,704	IBD outpatients in Canadian National Population Health Survey, 1998-99	• Employment status	Yes (IBD versus controls)	• IBD patients 20% more likely to be unemployed than controls (OR 1.20, CI 1.19-1.21)
Longobardi, 2003[47]	N=187 (cases) Controls=23,649	IBD outpatients in National Health Interview Study (US), 1999	• Employment status	Yes (symptomatic IBD versus controls)	• 31.5% of patients with symptomatic IBD unemployed compared with 14.8% of controls • 18.5% of patients with asymptomatic IBD unemployed

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Study	Subjects	Setting	Outcomes studied	Differences identified?	Relevant data
					compared with 14.8% of controls (P=NS)
Mayberry, 1992[49]	N=58 (cases) Controls=50	CD outpatients	• Employment status • Perceived occupational discrimination	Yes (IBD versus controls)	• 50% of IBD subjects had experienced long-term unemployment versus 24% of controls
Reinisch, 2007[51]	N=728	UC outpatients enrolled in clinical trial	• Employment status • Disability	Yes (UC in remission versus UC not in remission)	• 20.6% of subjects with UC in remission regained employed at week 30 versus 8.3% with UC not in remission • 41.2% of subjects with UC in remission received disability compensation at week 30 versus 80.0% with UC not in remission
Russel, 2003[50]	N=781 CD=311 UC=424 IC=46 Controls=824	IBD outpatients in population-based epidemiologic study (Netherlands)	• Ability to obtain health insurance • Ability to obtain life insurance	Yes (IBD versus controls)	• 16% of IBD patients versus 3% of controls had difficulty obtaining life insurance (OR 5.4, CI 2.3-13.0) • 66% of IBD patients versus 4% of controls had difficulty obtaining life insurance (OR 87, CI 31-246)
Straus, 2000[35]	N=552 AA=145 W=407	CD outpatients recruited from multiple clinics	• Days of work missed	Yes (race)	• AA missed mean 85 days of work per year, compared with 28 days per year for W

AA, African Americans; CD, Crohn's disease; CI, 95% confidence interval; IBD, inflammatory bowel disease; IC, indeterminate colitis; OR, odds ratio; UC, ulcerative colitis; W, whites