HHS Public Access

Author manuscript

Inflamm Bowel Dis. Author manuscript; available in PMC 2017 June 01.

Published in final edited form as:

Inflamm Bowel Dis. 2016 June ; 22(6): 1456–1461. doi:10.1097/MIB.0000000000000745.

Incidence of Crohn's Disease and Ulcerative Colitis in Rhode Island: Report from the Ocean State Crohn's and Colitis Area Registry (OSCCAR)

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Abstract

Background—Studies describing the incidence of Crohn's disease (CD) and ulcerative colitis (UC) are uncommon in the United States (US). We sought to determine the incidence of CD and UC in the state of Rhode Island (RI).

Methods—The Ocean State Crohn's and Colitis Area Registry (OSCCAR) is a state-based inception cohort of patients newly diagnosed with IBD in RI. To confirm a diagnosis of CD, UC or IBD unclassified (IBDU), the NIDDK IBD Genetics Consortium criteria were applied in a review of medical records from gastroenterology practices located in the state of RI and adjacent to the RI border in Massachusetts and Connecticut. Utilizing population-based data, we determined the statewide incidence of IBD in RI in 2008–2010.

Results—A total of 971 RI residents were diagnosed with IBD, including 444 with CD, 486 with UC and 41 with IBDU in 2008–2010. The overall age- and sex-adjusted IBD incidence was 30.2 (95% CI, 28.3–32.1) per 100,000 persons in this time frame with 13.9, 15.1 and 1.3 per 100,000 diagnosed with CD, UC and IBDU, respectively. Of the total incident cases in RI, 30% (n=291) were enrolled in OSCCAR for follow up.

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Conflict of Interest: The authors report no relevant conflicts of interest

Conclusion—The incidence of IBD in RI is higher than that previously reported by other population-based cohorts in the US. Prospective follow up of individuals enrolled in the community-based OSCCAR cohort is ongoing.

Keywords

Inflammatory Bowel Disease; Crohn's Disease; Ulcerative Colitis; Epidemiology; Incidence

Introduction

Inflammatory bowel diseases (IBD), typically classified as either Crohn's disease (CD) or ulcerative colitis (UC), are chronic, debilitating conditions characterized by relapsing and remitting episodes of gastrointestinal inflammation. As the incidence and prevalence have increased over the past 50 years, so has our understanding of the pathophysiology of this complex, immunologically-mediated disease process[1–3]. While various putative environmental risk factors have been implicated, an explanation for the increased rate of IBD diagnoses in the United States and abroad remains elusive[4,5]. Although data from developing countries are limited, recent reports suggest emergence of IBD as a global public health threat affecting newly industrialized nations in addition to more established, "westernized" populations[5,6].

A recent systematic review by Molodecky, *et al.* presents a comprehensive overview of population-based data from all relevant epidemiologic studies published in Europe, Asia, the Middle East and North America between 1950–2010[7]. While they report an estimated annual incidence rate of 19.2 per 100,000 persons of UC and 20.2 per 100,000 persons of CD in North America during this time frame, the US-specific data are mainly limited to findings reported from Olmsted County, Minnesota and a limited population of Northern California. In this light, the epidemiology of CD and UC has not been studied extensively in the United States (US). However, based on the available data from the US and Canada, these findings do suggest that the incidence and prevalence of IBD in North America are among the highest in the world.

In a review of the incidence and prevalence of the well-established cohort from Olmsted County, Loftus *et al.* reported the age and sex-adjusted annual incidence of UC and CD to be 8.8 per 100,000 and 7.9 per 100,000, respectively over a 10-year period from 1990–2000[8]. Herrinton, *et al.* reported annual incidence rates from the Kaiser Permanente Medical Care Program in Northern California between 1996–2002[9]. While the observed incidence of CD of 6.3 per 100,000 persons in this population was less than that reported in Olmsted County during a similar period, the incidence of UC of 12.0 per 100,000 persons was significantly higher. In contrast, a report from the European collaborative study evaluating the incidence of IBD across 20 centers in Europe between 1991–1993, found an overall age- and sex-adjusted incidence of 10.4 per 100,000 for UC and 5.6 per 100,000 for CD[10]. Thus, while the incidence of UC observed in California was similar to that in the European study, the incidence of CD appears to be higher, overall, in the US.

In Olmsted County, estimates are based on a unique medical records-linkage system (the Rochester Epidemiology Project) that captures approximately 90% of local residents. In

contrast, the Kaiser Permanente network provides care to an estimated 1/3 of the population in the San Francisco Bay region, Sacramento, and surrounding, less-urbanized communities. While Olmsted County is a relatively small, mostly Caucasian population, the Kaiser Permanente cohort represents a somewhat more diverse population. However, due to various geographic, demographic and methodological reasons, application of incidence data form these cohorts to the rest of the country may not be readily generalizable.

The Ocean State Crohn's and Colitis Area Registry (OSCCAR), is a state-based, prospective inception cohort of patients with IBD diagnosed in the state of Rhode Island (RI). The relatively diverse population of over 1 million, limited geographic range and well-circumscribed gastroenterology community were deemed to be excellent circumstances for establishing a prospective inception cohort of IBD patients in the US (see Supplemental Table 1). OSCCAR was originally designed to study the epidemiology of IBD, determine the incidence of IBD in RI and extrapolate these rates to the general population of the United States[11]. Utilizing population-based data obtained from OSCCAR we sought to estimate the statewide incidence of IBD in Rhode Island between 2008 and 2010.

Methods

Patient Enrollment

Overall, 97 of 98 practicing gastroenterologists and colorectal surgeons in Rhode Island agreed to refer patients to OSCCAR. Eleven gastroenterologists with practices in Massachusetts and Northern Connecticut just over the Rhode Island border also agreed to refer their newly diagnosed IBD patients who resided in Rhode Island. Enrollment began on January 1, 2008. All men, women, and children living in the state of Rhode Island with a newly confirmed diagnosis of CD, UC, or IBDU (inflammatory bowel disease, unspecified) were eligible for inclusion. Exclusion criteria included individuals diagnosed with CD, UC, or IBU prior to the study start date (i.e., prevalent cases), those unwilling or unable to provide informed consent for study participation and prisoners. Diagnosis of CD, UC, or IBDU was made by endoscopic, pathologic, or radiographic findings according to the criteria of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) IBD Genetics Consortium[12]. Institutional review board approval was obtained from all appropriate sites.

For those patients enrolled in OSCCAR, demographic, past medical history and disease-related information was recorded via interview and completion of standardized questionnaires during study visits with trained personnel. All information was confirmed by review of medical records. Additional data elements (including results from imaging, endoscopy, pathology and operative reports) were recorded after data abstraction by trained personnel through standardized chart review of the participant's medical record.

The Montreal classification system was used to describe disease phenotype at baseline[13]. Disease location in Crohn's disease was designated as L1 (ileal), L2 (colonic), or L3 (ileocolonic) with L4 as a modifier designating concomitant upper tract disease. Upper tract disease (L4) was based on endoscopic findings of inflammation and ulceration proximal to the ligament of Treitz. Behavior was defined as B1 (non-stricturing and non-penetrating), B2

(stricturing), or B3 (fistulizing/penetrating) with a P modifier to describe concomitant perianal disease. Ulcerative colitis disease location was described as E1 (proctitis), E2 (left sided disease), or E3 (pancolitis). Classifications were based on all available endoscopic, radiographic and surgical data obtained within 3 months of IBD diagnosis.

Ascertainment of Non-Enrolled Patients

To capture the total number of incident IBD cases in the state of Rhode Island between January 1, 2008 and December 31, 2010, exhaustive review of administrative (billing) data in participating practices was performed to identify patients with ICD-9 codes potentially mapping to IBD (see Supplemental Table II). At the time of data collection, not all practices in Rhode Island had adopted an electronic medical records system. In an effort to capture all diagnoses in a consistent manner, each practice's respective billing system was queried for such diagnostic codes. A previously conducted survey of 432 primary care providers (PCP) in the state of Rhode Island determined that the majority of such practitioners would refer a patient with symptoms concerning for a new diagnosis of IBD to a specialist for further workup and management[14]. Thus, PCP records were not considered in our incidence calculation. Cases were confirmed by chart review performed by trained data abstractors (RB, MM, HM). These data were used to estimate the age- and sex-specific incidence of CD, UC and IBDU in Rhode Island in 2008–2010. Due to HIPPA limitations, only data related to IBD diagnosis, age at diagnosis, and gender were collected from the medical records of patients not enrolled in OSCCAR. Additional IBD-specific data, such as Montreal Classifications, were not recorded due to these restrictions.

Data Analysis

We calculated the median age at diagnosis and estimated the age- and sex-specific incidence of CD, UC and IBDU in Rhode Island in 2008–2010. Annual incidence was defined as the number of new cases per year per 100,000 persons in the population. We assumed all Rhode Island residents to be at risk, in total 1,050,788 in 2008, 1,057,329 in 2009 and 1,052,567 in 2010[15]. The denominator of incidence was derived from publicly available population statistics for the state of Rhode Island. We standardized the estimated incidence directly according to the age- and sex-distribution of the total US population, using the 2010 Census[16]. The 95% confidence intervals (95% CI) for the age- and sex-adjusted incidence were calculated under the assumption that the number of IBD cases followed a Poisson distribution.

Results

Between 2008 and 2010, a total of 971 Rhode Island residents were diagnosed with IBD, including 444 with CD, 486 with UC and 41 with IBDU. Of those diagnosed with CD 193 (43%) were male and 235 (48%) of those with UC were female. The median age at diagnosis was 35 years (range, 2 to 99) for CD and 44 years (range, 7 to 93) for UC. Age at diagnosis was unknown in 5 cases (0.5%).

Adjusting for age and sex, the estimated annual IBD incidence was 30.2 (95% CI, 28.3–32.1) per 100,000 persons in the total population of Rhode Island in 2008–2010. There was

little variation noted during the 3 years studied. The incidence of IBD per 100,000 persons for 2008, 2009, and 2010 was 31.6, 30.4, and 30.3, respectively. Detailed data comparing enrolled and non-enrolled patients by year are presented in Supplementary Table 3. Table 1 shows the incidence separately for CD, UC and IBDU by sex and age group. The incidence of CD was higher among the female residents than the male residents (15.3 vs. 12.5 per 100,000 persons) while the incidence of UC was lower among females compared with males in Rhode Island (14.1 vs. 16.1 per 100,000 persons). Table 1 shows that the incidence proportions are greater for CD among the younger age groups, and for females aged 50–59 as well. The cumulative age-specific incidence for IBD, CD, and UC is graphically represented in Figure 1.

Of the 971 incident cases in Rhode Island, 291 (30%) patients were enrolled in OSCCAR. Of those not enrolled, 111 (11%) patients with a confirmed diagnosis of IBD were either unresponsive to repeated communications or not interested in participation. An additional 35 patients (4%) with a confirmed IBD diagnosis were deemed ineligible for study enrollment based on the exclusion criteria outlined above. The majority of these patients were either not Rhode Island residents or had been diagnosed with IBD for more than a year at the time of our chart review; two patients were incarcerated. While these patients did not meet inclusion criteria, they were considered in the incidence calculation if they resided in Rhode Island and were diagnosed with IBD between 2008 and 2010. Table 2 compares select demographic variables between enrolled and non-enrolled patients over the age of 18 years. In addition, disease location and behavior, as expressed by the Montreal Classification system, are presented for the OSCCAR cohort. The median age of diagnosis was 32.9 for those enrolled in OSCCAR versus 45.6 in the unenrolled patients. The observed younger age of OSCCAR is attributed to there being a single, academic Pediatric Gastroenterology practice in the state, of which the division chief (NSL) is a co-investigator of the study. During the 3-year timeframe, a total of 110 children under 18 were diagnosed with IBD, 84 (76%) of which were enrolled in OSCCAR. When restricting the analysis to those over the age of 18 at diagnosis, the median age of those enrolled (40.7) versus non-enrolled (46.9) was not appreciably different (Table 2).

While 174 (60%) of the total OSCCAR cohort were diagnosed with CD, 109 (37%) and 8 (3%) were diagnosed with UC and IBDU, respectively. Approximately half of the CD patients (n=87; 49%) presented with ileocolonic disease (L3). While the majority of CD patients (n=148; 83%) presented with inflammatory, non-stricturing, non-penetrating disease behavior (B1), 20% (n=36) and 10% (n=18) had concomitant upper tract and perianal disease, respectively at time of diagnosis. Half of those with UC (n=55; 50%) at enrollment presented with pancolitis (E3). Of those initially labeled IBDU, 6 (75%) have since been diagnosed with UC. Based on all available clinical information, the remaining 2 patients continue to meet diagnostic criteria for IBDU.

Discussion

In this near complete enumeration of IBD incident cases among the total population of Rhode Island, we found an overall age and sex-adjusted incidence of 30.2 per 100,000 persons for IBD, 13.9 per 100,000 persons for CD and 15.1 per 100,000 persons for UC in

2008–2010. These incidences are within the highest quintile rank of published incidence rates worldwide[7] and higher than those reported recently for specific populations in North America[8,9,17]. Similar to previous epidemiologic studies of IBD, we found a tendency towards a bi-modal age distribution[7,18,19].

The estimated incidence of CD in Rhode Island was higher than the reported CD incidence of 7.9 (95% CI, 6.3–9.5) per 100,000 person-years Loftus *et al.* found in Olmsted County, Minnesota in 1990–2000[8] and considerably higher than the rate of 6.3 (95% CI, 5.6–7.0) per 100,000 person-years Herrinton *et al.* demonstrated among members of Kaiser Permanente Medical Care Program in Northern California in 1996–2002[9]. Similarly, our results indicate that UC was more commonly diagnosed among the residents of Rhode Island than in the study populations from Northern California (12.0, 95% CI, 11.0–13.0 per 100,000 person-years)[9] and Olmsted County, Minnesota (8.8, 95% CI, 7.2–10.5 per 100,000 person-years)[8].

Population-based data from Olmsted County were obtained via retrospective review of a central medical records system that captures approximately 90% of local residents over a 3-year period. In comparison to Rhode Island, Olmsted County represents a smaller, somewhat less diverse, higher-educated population. In addition to 90% of residents identifying as non-Hispanic white, almost 30% are employed by the local health care system and are 1.5 times more likely to have a college education compared to the general population of the US[8]. Representing a larger, more diverse population, data from the Northern California cohort is limited to insurance claims from a single, albeit large, managed care organization. These data were limited to patients designated with an ICD-9 code for either CD (555.9) or UC (556.9) at a given clinical encounter. Accordingly, if a given condition is not addressed during the visit, the ICD-9 code is not recorded. Thus, in addition to the population being limited to members of a single health plan, there is a likelihood of missed cases given the narrow diagnostic criteria and fact that patients with inactive disease are less likely to be captured.

In contrast to the Olmsted County and Northern California cohorts, our data are reflective of nearly all new IBD diagnoses in the state of Rhode Island in 2008–2010. With cooperation from virtually all of the practicing gastroenterologists and general surgeons in the state and adjacent communities outside RI, OSCCAR began enrolling patients in January 2008. While not all patients diagnosed with IBD residing in Rhode Island were ultimately enrolled in the study, our incidence rates are based on a rigorous review of administrative billing data from all participating practices. A more thorough list of ICD-9 codes that may map to an IBD diagnosis was considered (see Supplemental Table II) and all cases were confirmed by chart review. In addition, a survey evaluating the referral patterns of primary care physicians in Rhode Island found that the majority of providers, when confronted with a patient with potential IBD, were very likely to refer to a specialist for further evaluation[14]. Thus, among the referral practices included, it is unlikely that many incident cases were missed. While practices in Massachusetts near the Rhode Island border that may care for Rhode Island residents were included, it is possible that some patients sought care out of state in practices not considered in our review.

The high incidence of IBD we observed in Rhode Island is likely multifactorial in nature. As recent literature[7] describes a steady increase in IBD diagnoses over time, it is possible that our cohort is reflective of this worldwide trend. Furthermore, the methodological rigor used to capture every diagnosis, regardless of enrollment in OSCCAR, is also a contributing factor. Given the well-defined geography of Rhode Island and thus accessibility of practitioner data, our cohort may more accurately reflect the true incidence of IBD in our study population as compared to larger populations such as Olmsted County and Northern California, where capturing each diagnosis represents a larger methodological challenge.

The population of the US in 2010 was approximately 309 million persons[15]. While the population of Rhode Island does not accurately reflect the population of the US as it relates to variations in geography, environmental exposures, and socioeconomic factors, if we were to extrapolate our estimated incidence in Rhode Island of 30.2 per 100,000 persons to the US population at that time, we would expect roughly 90,000 new cases of IBD (42–44,000 CD cases; 46–48,000 UC cases) each year in the United States. Existing evidence suggests that both CD and UC are still more common among Caucasians than among African-Americans, Asians and Hispanics, although the incidence of these diseases may be rising in these population segments[20]. We were unable to reliably ascertain race for patients not enrolled in OSCCAR. However, given the higher proportion of Caucasians living in Rhode Island compared with the US as a whole (81% versus the 72% in 2010; Suppl. Table I), the nationwide incidence of IBD might be somewhat lower than what we found in Rhode Island. We also note that smoking, identified as an important environmental factor in IBD with differing effects in UC and CD,[21,22,23] may be less prevalent in Rhode Island than elsewhere in the US according to publicly available survey data[24]. This could distort an extrapolation of IBD incidence in Rhode Island to the total US population. Finally, our data cover newly diagnosed cases in Rhode Island over a three year period; hence our results could be affected by short term fluctuations in the statewide occurence of IBD.

Of the 971 patients newly diagnosed with IBD between 2008 and 2010, 291 (30%) were enrolled in OSCCAR. Thus, from an epidemiologic standpoint, OSCCAR represents a community-based cohort. However, there is only a single, academic Pediatric Gastroenterology practice in the state. As we enrolled 76% of new cases under 18 years of age at diagnosis, the pediatric segment of the OSCCAR cohort more closely represents a population-based sample. Of those enrolled, detailed clinical data related to disease phenotype, behavior, activity, treatment, outcomes and quality of life continue to be prospectively collected. In addition, biospecimens such as blood, urine and stool were obtained at study enrollment (diagnosis) and continue to be collected longitudinally. As prospective data collection from this novel cohort continues, OSCCAR represents a unique opportunity to study the natural history and course of IBD over time[25–28]. Other studies will continue to utilize the collected biospecimens to address translational questions[29].

In conclusion, the observed incidence of IBD in Rhode Island is among the highest in the world. Ongoing prospective follow-up of individuals enrolled in the community-based OSCCAR cohort will provide a basis for predictive models of IBD prognosis over time.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

This work was supported by CCFA/CDC 5U01DP004785-02

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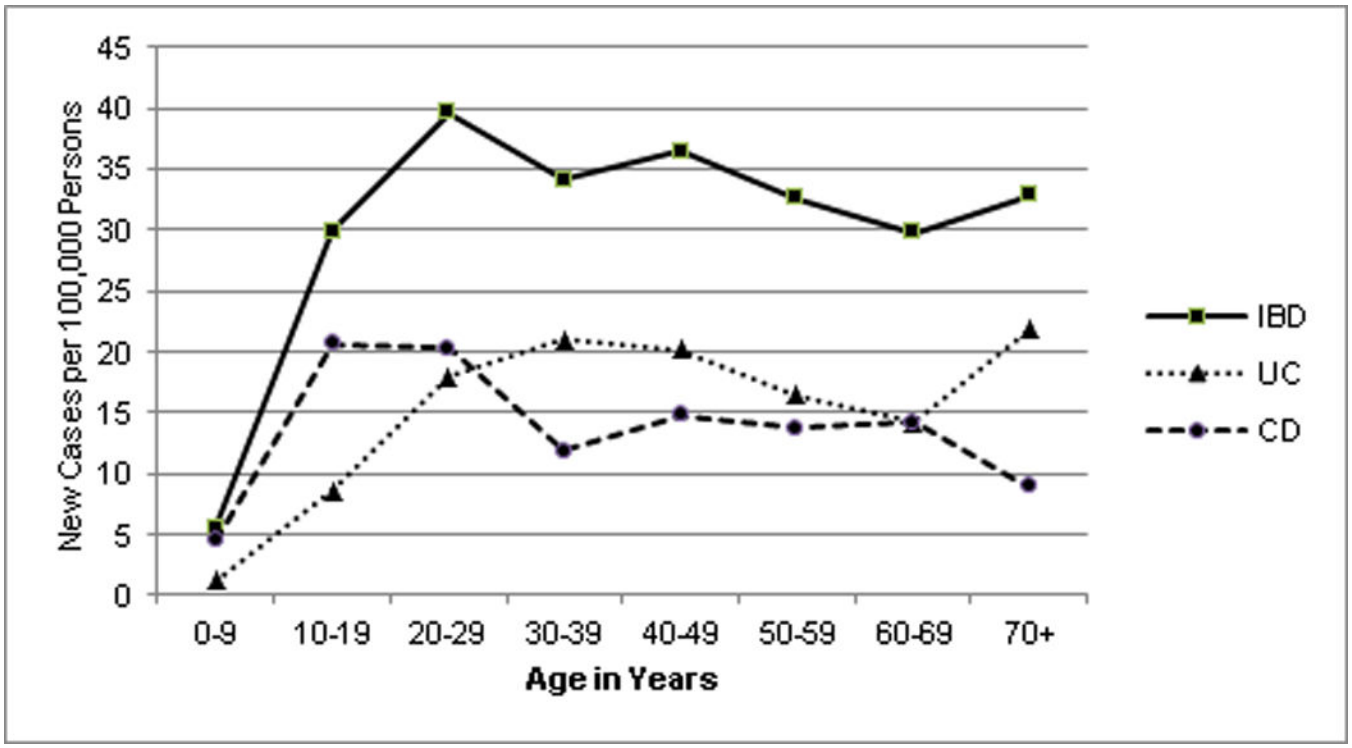

Figure 1.

Table 1

Incidence and number of cases of Crohn's disease and ulcerative colitis per 100,0000 persons in the State of Rhode Island, stratified by sex and age, 2008–2010.

		Crohn's Disease		Ulcerative Colitis		IBDU	
		Males Incidence	Females Incidence	Males Incidence	Females Incidence	Males Incidence	Females Incidence
Age Group, Years							
	0–9	3.8 (7)	5.1 (9)	1.1 (2)	1.1 (2)	0.0 (0)	0.0 (0)
	10–19	23.8 (52)	17.4 (37)	10.1 (22)	7.1 (15)	0.9 (2)	0.5 (1)
	20–29	15.5 (34)	25.7 (55)	17.7 (39)	18.7 (40)	0.5 (1)	1.4 (3)
	30–39	8.3 (16)	15.2 (30)	19.7 (38)	22.3 (44)	1.0 (2)	1.5 (3)
	40–49	13.4 (31)	16.1 (39)	21.7 (50)	18.6 (45)	1.7 (4)	1.2 (3)
	50–59	11.1 (24)	16.1 (37)	20.9 (45)	12.2 (28)	3.2 (7)	1.8 (4)
	60–69	11.4 (16)	16.8 (26)	15.7 (22)	12.9 (20)	2.1 (3)	0.7 (1)
	70 +	10.3 (13)	8.0 (16)	25.4 (32)	19.4 (39)	3.2 (4)	1.5 (3)
	Unknown	(0)	(2)	(1)	(2)	(0)	(0)
	Total	12.6 (193)	15.4 (251)	16.4 (251)	14.4 (235)	1.5 (23)	1.1 (18)
Age-Adjusted (95% CI)*		12.5 (10.7–14.3)	15.3 (13.4–17.2)	16.1 (14.1–18.1)	14.1 (12.3–15.9)	1.5 (0.9–2.1)	1.1 (0.6–1.6)
Age- and Sex-Adjusted (95% CI)**		**13.9 (12.6–15.2)**		**15.1 (13.7–16.4)**		**1.3 (0.9–1.6)**	

*Standardized to the age distribution of the total United States population in 2010, according to Census Bureau data.[15]

**Standardized to the age and sex distribution of the total United States population in 2010, according to Census Bureau data.[15]

CI, confidence interval.

Table 2

Comparison of OSCCAR vs. Non-Enrolled Patients Newly Diagnosed with IBD in Rhode Island: 2008–2010[#]

	OSCCAR N=207[#]	Non-Enrolled Patients N=654[#]
Age, (Mean, range)	40.8, 18–87	47, 18–99
Sex, N (%)		
Male	85 (41)	320 (49)
Female	122 (59)	334 (51)
Race, N (%)		
White	189 (91)	N/A
African American	8 (4)	N/A
Multiracial	3 (1)	N/A
Other	6 (3)	N/A
Refused/Unknown	1 (<1)	654 (100)
Ethnicity, N (%)		
Not Hispanic or Latino	195 (94)	N/A
Hispanic or Latino	11 (5)	N/A
Refused/Unknown	1 (<1)	654 (100)
Diagnosis		
CD, N (%)	111 (54)	251 (38)
Disease Location[%]		
L1 – Ileal	24 (22)	N/A
L2 – Colonic	33 (30)	N/A
L3 - Ileocolonic	53 (48)	N/A
L4[*%]**-Upper tract**	11 (10)	N/A
Disease Behavior[%]		
B1 – Inflammatory	93 (84)	N/A
B2 – Stricturing	13 (12)	N/A
B3 – Penetrating	5 (5)	N/A
P[*] **– Perianal**	5 (5)	N/A
UC, N (%)	91 (44)	368 (56)
E1 – Proctitis	21 (23)	N/A
E2 – Left sided	28 (31)	N/A
E3 - Pancolitis	42 (46)	N/A
IBDU, N (%)	5(2)	35(5)

[*] Designates isolated or concomitant upper tract (L4) or concomitant perianal disease (P)

[%] Designates that n=1 patients had isolated upper tract disease (L4) at diagnosis

[#] Pediatric patients excluded (n=110) due to 76% enrollment in OSCCAR