Black/African American Patients with Pediatric Crohn's Disease Report Less Anxiety and Fatigue than White Patients

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Objectives To compare patient-reported outcomes in black/African American patients with white patients participating in IBD Partners Kids & Teens, in order to identify possible racial healthcare disparities in pediatric inflammatory bowel disease (IBD) as future targets for improvement.

Study design This was a cross-sectional analysis comparing patient-reported outcomes in black/African American patients with white patients, aged 9-18 years, with IBD participating in the IBD Partners Kids & Teens cohort from August 2013 to April 2018. Secondary outcomes included number of IBD-related hospitalizations and surgeries, current medication use, and disease activity.

Results We included 401 patients with Crohn's disease (white = 378 [94%]; black/African American = 23 [6%]). For children with Crohn's disease, black/African American patients compared with white patients reported less anxiety (40.7 vs 47.5, $P = .001$) and fatigue (44.3 vs 48.4, $P = .047$) despite more frequently reported treatment with biologics (91% vs 61%, $P = .006$) and antibiotics (17% vs 5%, $P = .03$) and history of hospitalizations (81% vs 52%, $P = .02$).

Conclusions Black/African American children with Crohn's disease were less likely to report anxiety or fatigue than white patients, despite an apparent more severe disease course reflected by greater reported frequency of treatment with biologics and antibiotics and history of hospitalizations. *(J Pediatr 2020;225:146-51)*.

Patient-reported outcomes (PROs) in subjects with inflammatory bowel disease (IBD) are increasingly an area of focus in the literature.[1] As a chronic, relapsing, and remitting disease, IBD may place a significant burden on the growing and developing child.[2] Pediatric patients with IBD may deal with potentially distressing symptoms and signs, such as diarrhea and growth delay, the burden and side effects of medications, and potential hospitalizations and surgeries.

Investigators have reported that lower disease activity,[3,4] longer disease duration,[5] less internalizing and externalizing symptoms,[6] and male sex[7] may be associated with better quality of life in patients with IBD. A study of adult patients with Crohn's disease (CD) found no differences in quality of life across race/ethnicity.[8] As the incidence of IBD is increasing in racial/ethnic minorities,[9,10] understanding racial/ethnic differences among PROs in patients with IBD may help to optimize management for patients and address racial and ethnic healthcare disparities.

Our primary study aim was to compare PRO measurements in black/African American children with white children with IBD using IBD Partners Kids & Teens, a Web-based cohort of pediatric patients with IBD focused on improving quality of life. Our secondary aim was to compare the number of IBD-related hospitalizations and surgeries, medication use, and disease activity in black/African American children compared with white children with IBD.

Methods

Study Design and Data Source

We performed a cross-sectional analysis to evaluate racial/ethnic differences in PROs, as well as number of IBD-related hospitalizations and surgeries, medication use, and disease activity, in pediatric patients with IBD (CD, ulcerative colitis [UC], IBD unspecified [IBD-U]). We analyzed data from pediatric patients

CD	Crohn's disease
IBD	Inflammatory bowel disease
IBD-U	Inflammatory bowel disease-unspecified
PRO	Patient-reported outcome
PROMIS	Patient-Reported Outcomes Measurement Information System
PUCAI	Pediatric Ulcerative Colitis Activity Index
sCDAI	Short Crohn's Disease Activity Index
UC	Ulcerative colitis

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Funded by the Crohn's and Colitis Foundation. M.L. is a consultant for Pfizer, Takeda, UCB, AbbVie, Janssen, Prometheus, Salix, Valeant, and TARGET PharmaSolutions. M.K. is a consultant for AbbVie and Janssen and owns shares in Johnson & Johnson. The other authors declare no conflicts of interest.

Portions of this study were presented at the Pediatric Academic Society annual meeting, April 24-May 1, 2019, Baltimore, MD.

https://doi.org/10.1016/j.jpeds.2020.05.042

aged 9-18 years diagnosed with IBD who were enrolled in IBD Partners Kids & Teens from August 2013 to April 2018.

IBD Partners Kids & Teens, sponsored by the Crohn's & Colitis Foundation, studies pediatric IBD and is aimed at improving quality of life for these patients.[11] Patients <18 years old with self-reported IBD and their parents are offered the opportunity to complete online surveys twice a year to report on IBD-related treatments, health behaviors, and outcomes. Patients are recruited through Crohn's & Colitis Foundation e-mail rosters as well as the Web site, word of mouth, social media, and promotional events.[12] Our study used the initial baseline survey designed for children at least 9 years of age.

We included all children who reported a race of either "black/African American" or "white." We excluded other races, those who did not report race/ethnicity, children younger than 9 years old (as they had a separate survey in which parent-proxy report PROs), and children 9 years old or older who did not complete any of the PROs.

Outcome Variables

We analyzed differences between black/African American and white patients for each outcome variable in patients with CD and in all patients with IBD (CD, UC, IBD-U) combined. The Patient-Reported Outcomes Measurement Information System (PROMIS), developed with funding from the National Institutes of Health, is a set of nondisease-specific instruments that can measure child-reported health and well-being.[13] In this study, we used PROMIS domains of anxiety, depression, fatigue, peer relationships, and pain interference ("the extent to which pain hinders engagement with social, cognitive, emotional, physical, and recreational activities").[14] PROMIS scores are calibrated using T scores, whereby a T score of 50 reflects the mean of the pediatric reference population with a standard deviation of 10.[15] Greater T scores indicate more of a given domain. For example, greater T scores for negatively worded domains, such as anxiety, indicate more anxiety. Greater T scores for positively worded domains, such as peer relationships, indicate better peer relationships.[15] The reference population is a diverse pediatric population of all racial/ethnic backgrounds and includes both healthy patients and patients with chronic diseases.[16] A minimally important difference is the smallest difference in scores to detect clinically important differences. It is estimated that the minimally important difference in PROMIS scores is "about 2 points, with a SE of a little over a half point, for the average clinician."[17]

Other outcome variables included IBD-related hospitalizations and surgeries, current use of medications (5-aminosalicylates, steroids, immunosuppressants, antibiotics, probiotics, and biologics, including infliximab, adalimumab, certolizumab pegol, golimumab, and vedolizumab), and disease activity status as measured by the short Crohn's Disease Activity Index (sCDAI) for CD and Pediatric Ulcerative Colitis Activity Index (PUCAI) for UC/IBD-U. The sCDAI assesses the child's general well-being over the past week, abdominal pain over the past week, and the number of liquid/very soft stools over the past 24 hours.[18] A sCDAI score of <150 indicates remission, 150-219 indicates mild disease, 220-450 indicates moderate disease, and >450 indicates severe disease. The PUCAI assesses abdominal pain, rectal bleeding, stool consistency, stooling causing wakening from sleep at night, and activity level over the past 2 days and number of stools over the past 24 hours.[19] A PUCAI score of 0-9 indicates remission, 10-34 indicates mild disease, 35-64 indicates moderate disease, and 65-85 indicates severe disease.

Statistical Analyses

Patient demographic and clinical characteristics were described as n (%) and mean (SD) or median [IQR]. Comparisons between black/African American and white patients were made by χ^2/Fisher exact tests or independent 2-sample Student *t* tests/Wilcoxon rank-sum tests. All *P* values were 2-sided with statistical significance evaluated at the 0.05 alpha level. Analyses were performed in R version, 3.5.3 (R Foundation for Statistical Computing, Vienna, Austria).

Ethical Approval

The IBD Partners Kids & Teens study protocol was reviewed and approved by the institutional review board of the University of North Carolina at Chapel Hill (Chapel Hill, North Carolina).

Results

Patient Demographics

A total of 512 patients (401 CD, 99 UC, 12 IBD-U) qualified for our study (**Table I**), after we excluded 128 patients who identified as a race/ethnicity other than black/African American or white or skipped the question related to race/ethnicity, 34 patients who were <9 years old, and 279 patients ≥9 years old who did not complete PROs.

In children with CD, median age at time of diagnosis did not differ in black/African American (10.0 years [IQR 9.0-11.0]) vs white patients (10.0 years [IQR 8.25-12.0]; *P* = .80). Median time since diagnosis at completion of survey did not differ in black/African American (3.0 years [IQR 2.5-6.5] vs white patients (4.0 years [IQR 3.0-6.0] *P* = .67).

In children in the combined IBD group (CD, UC, IBD-U), median age at time of diagnosis did not differ in black/African American (10.0 years [IQR 9.0-11.5]) vs white (11.0 years [IQR 8.0-12.0]) patients (*P* = .75). Median time since diagnosis at completion of survey did not differ in black/African American (4.0 years [IQR 2.5-6.5] vs white (4.0 years [IQR 3.0-6.0]) patients (*P* = .90).

PROMIS Domains

Black/African American patients with CD reported lower mean levels of anxiety and fatigue compared with white patients (**Table II**). For all IBD subtypes combined, black/African American patients reported lower mean levels of anxiety compared with white patients. No statistically significant differences were found in the other PROMIS

Table I. Demographics

	CD N = 401			UC N = 99			All IBD* N = 512		
	B/AA	W		B/AA	W		B/AA	W	
Demographics	23 (5.7)†	378 (94.3)	*P*	4 (4.0)	95 (96.0)	*P*	27 (5.3)	485 (94.7)	*P*
Sex									
F	9 (39.1)	163 (43.1)	.87	3 (75.0)	49 (51.6)	.62	12 (44.4)	217 (44.7)	.99
M	14 (60.9)	215 (56.9)		1 (25.0)	46 (48.4)		15 (55.6)	268 (55.3)	
Age, y‡									
9-11	3 (13.0)	49 (13.0)	.99	0 (0)	14 (14.7)	.99	3 (11.1)	63 (13.0)	.99
≥12	20 (87.0)	329 (87.0)		4 (100)	81 (85.3)		24 (88.9)	422 (87.0)	

B/AA, black/African American; *F*, female; *M*, male; *W*, white.
*IBD-U findings: B/AA 0 (0%), W 12 (100%); 5 female (41.7%), 7 male (58.3%); aged 9-11 years: 6 (54.5%), age ≥12 years: 5 (45.4%).
†n (%).
‡Age (years) refers to current age at time of survey.

measures between black/African American and white patients with IBD.

IBD-Related Hospitalizations and Surgeries

Black/African American patients with CD reported more IBD-related hospitalizations than white patients (Table III); however, there was no racial/ethnic difference observed in reported frequency of IBD-related surgeries. IBD-related hospitalizations did not differ in black/African American patients compared with white patients in the all IBD subtypes–combined group.

Medications

A total of 62.3% of patients with CD and 56.1% of patients with IBD reported treatment with biologic agents (Table IV). A total of 21.9% of patients with CD and 28.1% of patients with IBD reported 5-aminosalicylate use. Black/African American patients with CD reported significantly more frequent use of biologics and antibiotics compared with white patients. White patients with CD reported significantly more frequent use of 5-aminosalicylates compared with black/African American patients.

In the all IBD combined group, black/African American patients reported significantly more frequent use of biologics compared with white patients. White patients reported significantly more frequent use of 5-aminosalicylates and probiotics compared with black/African American patients. There was no significant difference in medication use between racial groups for the remainder of the surveyed medications in CD or all IBD combined.

Disease Activity

A total of 382 (95.3%) patients with CD (22 [5.8%] black/African American, 360 [94.2%] white) provided responses for current disease activity (sCDAI scores). Disease activity did not differ between black/African American compared with white patients in CD ($P = .81$): 19 (86.4%) black/African American patients vs 298 (82.8%) white patients were in remission, 3 (13.6%) black/African American vs 44 (12.2%) white patients had mild disease, 0 (0%) black/African American vs 18 (5.0%) white patients had moderate disease, and no black/African American or white patients had severe disease.

A total of 436 (85.2%) patients with IBD (24 [5.5%] black/African American, 412 [94.5%] white) provided responses for current disease activity (sCDAI scores, PUCAI scores). Disease activity did not differ between black/African American compared with white patients in IBD (all subtypes combined) ($P = .78$): 20 (83.3%) black/African American patients vs 320 (77.7%) white patients were in remission, 4 (16.7%) black/African American vs 70 (17.0%) white patients had mild disease, 0 (0%) black/African American vs 21 (5.1%) white patients had moderate disease, and 0 (0%)

Table II. PROMIS T scores

	CD			All IBD		
PROMIS domains	B/AA N* = 23	W N = 378	*P*	B/AA N = 27	W N = 485	*P*
Anxiety	40.7 (8.2)†	47.5 (10.8)	.001	42.7 (11.1)	47.9 (10.7)	.023
Depression	40.8 (7.3)	43.7 (8.7)	.079	41.4 (9.4)	44.2 (8.9)	.16
Fatigue	44.3 (8.9)	48.4 (12.0)	.047	45.5 (11.2)	49.3 (12.2)	.11
Pain Interference	49.4 (13.0)	46.9 (11.1)	.37	48.3 (12.6)	47.6 (11.3)	.77
Peer Relationships	48.6 (12.5)	48.9 (9.2)	.91	48.5 (12.2)	48.8 (9.3)	.90

*Total number of participants that responded to at least 1 of the PROMIS Domain questions. Less than 1% of data are missing.
†Mean T score (SD).

Table III. IBD-related hospitalizations and surgeries

Hospitalizations and surgeries	CD B/AA N = 21	CD W N = 374	CD P	All IBD B/AA N = 24	All IBD W N = 480	All IBD P
Number of hospitalizations						
0	4 (19.0)*	178 (47.6)	.02	5 (20.8)	217 (45.2)	.057
1	6 (28.6)	86 (23.0)		7 (29.2)	109 (22.7)	
≥2	11 (52.4)	110 (29.4)		12 (50.0)	154 (32.1)	
	B/AA N = 23	**W N = 378**	**P**	**B/AA N = 27**	**W N = 485**	**P**
Number of surgeries						
0	17 (73.9)	307 (81.2)	.55	21 (77.8)	394 (81.2)	.65
1	4 (17.4)	44 (11.6)		4 (14.8)	48 (9.9)	
≥2	2 (8.7)	27 (7.1)		2 (7.4)	43 (8.9)	

*n (%).

black/African American vs 1 (0.2%) white patient had severe disease.

Discussion

We compared PROs as well as IBD-related hospitalizations, surgeries, medications, and disease activity between black/African American and white pediatric patients in a large, national, cross-sectional study using IBD Partners Kids & Teens data. We found that black/African American patients with CD reported better anxiety and fatigue scores. However, taken together, our findings suggest a more severe disease course in black/African American patients with CD, as hospitalizations, biologic use and antibiotic use were reported more frequently by black/African American patients with CD, whereas 5-aminosalicylate use was more commonly reported by white patients with CD.

We expected to see worse PROs for black/African American because our data suggest an overall more severe disease course in blacks/African Americans with CD, as noted previously. Our finding of worse mean PROMIS scores with worse disease activity scores in all IBD subtypes combined (data not shown) is consistent with a previous study of IBD Partners Kids & Teens data, whereby mean PROMIS scores were significantly worse for patients with CD with worse disease activity by sCDAI.[12] Although we found no overall difference in disease activity indices between black/African American and white patients, disease activity indices provide an instantaneous assessment of disease severity, and other measures, such as history of hospitalizations and medication use, may provide a more comprehensive, longer-term picture of the severity of a patient's disease. One possible explanation for our findings is that perhaps patients have improved quality of life PROs while on biologic agents.[20-22] Racial differences in PROs may additionally be due to racial differences in perspectives regarding mental health.[23] It is possible that our black/African American patients may have been concerned about stigma when reporting mental health outcomes despite that their responses were anonymous.[23] Other explanations may include increased resilience in black/African American children,[24] differences in understanding of disease,[25,26] or

Table IV. Medication use

Current medications	CD N = 401 B/AA N = 23	CD N = 401 W N = 378	CD P	All IBD N = 512 B/AA N = 27	All IBD N = 512 W N = 485	All IBD P
5-Aminosalicylates	0 (0)*	88 (23.3)	.018	1 (3.7)	143 (29.5)	.007
Steroids	3 (13.0)	44 (11.6)	.74	3 (11.1)	59 (12.2)	.99
Immunosuppressants	5 (21.7)	140 (37.0)	.21	6 (22.2)	169 (34.8)	.26
Antibiotics	4 (17.4)	18 (4.8)	.03	4 (14.8)	28 (5.8)	.08
Probiotics	2 (8.7)	97 (25.7)	.11	2 (7.41)	138 (28.5)	.03
Biologics†	21 (91.3)	229 (60.6)	.006	24 (88.9)	263 (54.2)	.001
Infliximab	14 (60.9)	162 (42.9)	.14	16 (59.3)	189 (39.0)	.058
Adalimumab	6 (26.1)	56 (14.8)	.15	7 (25.9)	61 (12.6)	.07
Certolizumab pegol	0 (0)	4 (1.1)	.99	0 (0)	4 (0.8)	.99
Golimumab	0 (0)	1 (0.3)	.99	0 (0)	1 (0.2)	.99
Vedolizumab	1 (4.4)	6 (1.6)	.34	1 (3.7)	8 (1.7)	.39

*n (%).
†Biologics heading refers to summation of the biologics listed in the table, including infliximab, adalimumab, certolizumab pegol, golimumab, and vedolizumab.

decreased psychiatric comorbidity.[27] Prospective studies should further examine these variables.

Although we have not identified other published studies examining PRO differences in pediatric IBD by race/ethnicity for comparison, a study examining quality of life PROs in CD adults did not identify racial/ethnic differences.[8] Although the surveys used in this adult study included questions related to anxiety and fatigue, the final reported scores do not distinguish the specific domains of anxiety, depression, fatigue, pain interference, and peer relationships, as PROMIS does, thereby making a direct comparison to our study difficult. As PROs are a treatment target for IBD,[28] it is essential that we better understand racial/ethnic differences in these important outcomes in the pediatric IBD population.

Similar to our findings, other studies have suggested that black/African Americans with CD have a more severe disease course. A retrospective study using data from the Pediatric Health Information System found that black/African American children with CD were more frequently treated with biologics.[29] This finding was thought to be due to more aggressive disease behavior in black/African American children, because black/African American children were found to have greater rates of perianal disease and greater need for perianal/perineal procedures, greater need for endoscopies, and greater rates of anemia requiring transfusions. This study additionally found that readmissions were more frequent in black/African American patients compared with white patients possibly due to financial barriers to access outpatient care due to lower income and Medicaid insurance in blacks/African American patients. We did not have data to assess income and insurance in our study. As previous studies have shown that worse disease activity is associated with worse quality of life,[3,4] our findings suggest that other unidentified variables are contributing to the better PROs in black/African American patients with CD.

In contrast, a study from the ImproveCareNow network found no racial/ethnic differences in medical treatment for children with CD in the first year since diagnosis.[30] Despite apparent more severe disease activity as assessed by physician global assessment in this study, black/African American patients were not more likely to be treated with biologics, possibly indicating under treatment of disease. Black/African American children were more likely to have Medicaid insurance, which may help to explain this finding. Treatment decisions also may reflect differences in response to previous medications. Our patient cohort was farther out from diagnosis than participants in the ImproveCareNow study, which may contribute to the difference in results. In addition, our cohort was a select group that self-initiated participation, and is less likely a reflection of the general pediatric IBD population.

Our study has several strengths. We included a large, national sample of patients. Our findings help to identify possible racial healthcare disparities in a pediatric chronic inflammatory condition, which may serve as targets for future research. By identifying racial disparities, we can work toward improving patient outcomes for all patients.

Limitations of our study include that findings from the IBD Partners Kids & Teens cohort may not be generalizable to the broader US pediatric IBD population. Our cohort may differ in meaningful ways compared with those who chose not to participate or were unaware of the opportunity. For example, our study had a smaller proportion of black/African American patients (5%) compared with other studies (6%-12%).[26,31,32] It is possible that mistrust in health science research in the black/African American community may deter participation in IBD Partners Kids & Teens.[33] Furthermore, our patient population is skewed toward those with greater education and greater socioeconomic class, as well as greater accessibility to a computer, which is the means of recruitment and data collection. In addition, the survey is only in English, thereby limiting participation to English speakers. Finally, the study includes a large proportion of patients in remission by sCDAI and PUCAI, and our patients may have better PROs than the general pediatric IBD population, as suggested by the PROMIS T score results in our study.

Furthermore, our study was exploratory in nature and not powered for all comparisons; therefore, a lack of significance does not indicate that a true relationship does not exist. We did not make comparisons within UC and IBD-U due to small sample sizes. When we combined all IBD subtypes together, we had different findings than when analyzing CD alone. This may be due to inherent differences between different IBD subtypes, suggesting that each IBD subtype should be independently investigated in future studies. In addition, adjustment for multiple comparisons was not made and significance found could potentially be by chance. As with any cross-sectional study, our data reflect only one point in time and do not capture the full scope of the patients' disease status and course. Specifically, our data were collected from participants' baseline survey and reflect current responses to PROMIS questions, past hospitalizations and surgeries, current medication use, and current disease activity level. Similar to our previous study on racial/ethnic differences in pediatric IBD,[34] neither indications for medical treatment nor length of exposure to medications were reported. Future studies should consider genetics and environmental exposures such as diet, birth country, and number of years residing in US in evaluation of PRO differences. In addition, future prospective longitudinal studies are needed with a larger group of patients and should include pediatric specific disease activity indices as well as account for possible confounders such as geographic location, time of year/season, history of mental health disease, socioeconomic status, insurance status, and access to healthcare.

Prospective longitudinal studies are required in a larger number of patients to further investigate racial/ethnic differences in pediatric IBD, with a focus on PROs, to help understand the etiology of our findings. ■

Submitted for publication Feb 18, 2020; last revision received May 18, 2020; accepted May 20, 2020.

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Data statement

Data sharing statement available at www.jpeds.com.

References

1. Williet N, Sandborn WJ, Peyrin-Biroulet L. Patient-reported outcomes as primary end points in clinical trials of inflammatory bowel disease. Clin Gastroenterol Hepatol 2014;12:1246-56.
2. Mackner LM, Greenley RN, Szigethy E, Herzer M, Deer K, Hommel KA. Psychosocial issues in pediatric inflammatory bowel disease: report of the North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition. J Pediatr Gastroenterol Nutr 2013;56:449-58.
3. Abdovic S, Mocic Pavic A, Milosevic M, Persic M, Senecic-Cala I, Kolacek S. The IMPACT-III (HR) questionnaire: a valid measure of health-related quality of life in Croatian children with inflammatory bowel disease. J Crohns Colitis 2013;7:908-15.
4. Otley A, Smith C, Nicholas D, Munk M, Avolio J, Sherman PM, et al. The IMPACT questionnaire: a valid measure of health-related quality of life in pediatric inflammatory bowel disease. J Pediatr Gastroenterol Nutr 2002;35:557-63.
5. Otley AR, Griffiths AM, Hale S, Kugathasan S, Pfefferkorn M, Mezoff A, et al. Health-related quality of life in the first year after a diagnosis of pediatric inflammatory bowel disease. Inflamm Bowel Dis 2006;12:684-91.
6. Gray WN, Denson LA, Baldassano RN, Hommel KA. Disease activity, behavioral dysfunction, and health-related quality of life in adolescents with inflammatory bowel disease. Inflamm Bowel Dis 2011;17:1581-6.
7. Casellas F, López-Vivancos J, Casado A, Malagelada JR. Factors affecting health related quality of life of patients with inflammatory bowel disease. Qual Life Res 2002;11:775-81.
8. Ghazi LJ, Lydecker AD, Patil SA, Rustgi A, Cross RK, Flasar MH. Racial differences in disease activity and quality of life in patients with Crohn's disease. Dig Dis Sci 2014;59:2508-13.
9. Ogunbi SO, Ransom JA, Sullivan K, Schoen BT, Gold BD. Inflammatory bowel disease in African-American children living in Georgia. J Pediatr 1998;133:103-7.
10. Afzali A, Cross RK. Racial and ethnic minorities with inflammatory bowel disease in the United States: a systematic review of disease characteristics and differences. Inflamm Bowel Dis 2016;22:2023-40.
11. IBD Partners Kids & Teens. 2019. https://cgibd.med.unc.edu/ccfapartners/. Accessed June 26, 2019.
12. Arvanitis M, DeWalt DA, Martin CF, Long MD, Chen W, Jaeger B, et al. Patient-reported outcomes measurement information system in children with Crohn's disease. J Pediatr 2016;174:153-9.
13. Intro to PROMIS. HealthMeasures. 2019. http://www.healthmeasures.net/explore-measurement-systems/promis/intro-to-promis. Accessed June 26, 2019.
14. List of Pediatric Measures. HealthMeasures. 2019. http://www.healthmeasures.net/explore-measurement-systems/promis/intro-to-promis/list-of-pediatric-measures. Accessed June 26, 2019.
15. PROMIS. HealthMeasures. 2019. http://www.healthmeasures.net/score-and-interpret/interpret-scores/promis. Accessed June 26, 2019.
16. Irwin DE, Stucky BD, Thissen D, Dewitt EM, Lai JS, Yeatts K, et al. Sampling plan and patient characteristics of the PROMIS pediatrics large-scale survey. Qual Life Res 2010;19:585-94.
17. Thissen D, Liu Y, Magnus B, Quinn H, Gipson DS, Dampier C, et al. Estimating minimally important difference (MID) in PROMIS pediatric measures using the scale-judgement method. Qual Life Res 2016;25:13-23.
18. Thia K, Faubion WA Jr, Loftus EV Jr, Persson A, Sanborn WJ. Short CDAI: development and validation of a shortened and simplified Crohn's disease activity index. Inflamm Bowel Dis 2011;17:105-11.
19. Turner D, Otley AR, Mack D, Hyams J, De Bruijne J, Uusoue K, et al. Development, validation, and evaluation of a pediatric ulcerative colitis activity index: a prospective multicenter study. Gastroenterology 2007;133:423-32.
20. Dillman JR, Carlos RC, Smith EA, Davenport MS, De Matos Maillard V, Adler J. Relationship of small bowel MR imaging to health-related quality of life measures in newly diagnosed pediatric small bowel Crohn's disease. Radiology 2016;280:568-75.
21. Feagen BG, Yan S, Bala M, Bao W, Lichtenstein GR. The effects of infliximab maintenance therapy on health-related quality of life. Am J Gastroenterol 2003;98:2232-8.
22. Loftus EV, Feagan BG, Colombel JF, Rubin DT, Wu EQ, Yu AP, et al. Effects of adalimumab maintenance therapy on health-related quality of life of patients with Crohn's disease: patient-reported outcomes of the CHARM trial. Am J Gastroenterol 2008;103:3132-41.
23. Ward E, Wiltshire JC, Detry MA, Brown RL. African American men and women's attitude toward mental illness, perceptions of stigma, and preferred coping behaviors. Nurs Res 2013;62:185-94.
24. Webber KC, Smokowski PR. Assessment of adolescent optimism: measurement invariance across gender and race/ethnicity. J Adolesc 2018;68:78-86.
25. Selinger CP, Lal S, Eaden J, Jones DB, Katelaris P, Chapman G, et al. Better disease specific knowledge is associated with greater anxiety in inflammatory bowel disease. J Crohns Colitis 2013;7:214-8.
26. Barnes EL, Kochar B, Long MD, Martin CF, Kappelman MD. Minority pediatric patients with inflammatory bowel disease demonstrate an increased length of stay. Inflamm Bowel Dis 2017;23:2189-96.
27. Engelmann G, Erhard D, Petersen M, Parzer P, Schlarb AA, Resch F, et al. Health-Related quality of life in adolescents with inflammatory bowel disease depends on disease activity and psychiatric comorbidity. Child Psychiatry Hum Dev 2015;46:300-7.
28. Peyrin-Biroulet L, Sandborn W, Sands BE, Reinisch W, Bemelman W, Bryant RV, et al. Selecting Therapeutic Targets in Inflammatory Bowel Disease (STRIDE): determining therapeutic goals for treat-to-target. Am J Gastroenterol 2015;110:1324-38.
29. Dotson JL, Kappelman MD, Chisolm DJ, Crandall WV. Racial disparities in readmission, complications, and procedures in children with Crohn's disease. Inflamm Bowel Dis 2015;21:801-8.
30. Dotson JL, Cho M, Bricker J, Kappelman MD, Chisolm DJ, Tomer G, et al. Race differences in initial presentation, early treatment, and 1-year outcomes of pediatric Crohn's disease: results from the ImproveCareNow Network. Inflamm Bowel Dis 2017;23:767-74.
31. Abramson O, Durant M, Mow W, Finley A, Kodali P, Wong A, et al. Incidence, prevalence, and time trends of pediatric inflammatory bowel disease in Northern California, 1996 to 2006. J Pediatr 2010;157:233-9.
32. Adamiak T, Walkiewicz-Jedrzejczak D, Fish D, Brown C, Tung J, Khan K, et al. Incidence, clinical characteristics, and natural history of pediatric IBD in Wisconsin: a population-based epidemiological study. Inflamm Bowel Dis 2013;19:1218-23.
33. Scharff DP, Mathews KJ, Jackson P, Hoffsuemmer J, Martin E, Edwards D. More than Tuskegee: understanding mistrust about research participation. J Health Care Poor Underserved 2010;21:879-97.
34. Li BH, Guan X, Vittinghoff E, Gupta N. Comparison of the presentation and course of pediatric inflammatory bowel disease in South Asians with Whites: a single center study in the United States. J Pediatr 2013;163:1211-3.