Experiences of Ethnic Minority Patients Who Are Living with a Primary Bowel Condition or Bowel-Related Symptoms of Other Chronic Diseases: A Systematic Review

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Abstract

Background: Prevalence of chronic gastrointestinal diseases has been rising amongst ethnic minority populations in Western countries, despite the first-generation migrants originating from countries of low prevalence. Differences caused by genetic, environmental, cultural, and religious factors in each context may contribute towards shaping experiences of ethnic minority individuals living with primary bowel conditions. This review aimed to explore the experiences of ethnic minority patients' living with chronic bowel illnesses and bowel-related symptoms of other chronic diseases.

Methods: We systematically searched for qualitative, quantitative, and mixed methods studies on eight electronic databases and manually searched reference lists of frequently cited papers. Fifteen papers met the inclusion criteria: focussing on inflammatory bowel disease, irritable bowel syndrome, coeliac disease and prostate cancer survivors experiencing bowel symptoms.

Results: Core themes were narratively analysed. South Asians had limited understanding of their illness and language and literacy barriers, particularly older generations, suggesting a need for culturally relevant inflammatory bowel disease and coeliac disease information. Family support was limited, and Muslim South Asians referred to religion to understand and self-manage inflammatory bowel disease. Ethnic minority groups across countries experienced poor dietary intake for coeliac disease and inflammatory bowel disease, cultural conflict in self-managing diet for inflammatory bowel disease, increased anxiety, and the need for better quality of, and access to, healthcare services. UK ethnic minorities had problems with IBD diagnosis/misdiagnosis. Self-efficacy positively impacted bowel symptoms in prostate cancer survivors.

Conclusions: Cultural, religious, and social contexts, together with language barriers and limited health literacy influenced experiences of health inequalities for ethnic minorities with chronic bowel diseases.

Background

Bowel-related chronic illnesses have been rising in ethnic minority populations, though experiences of minority groups in this area have been largely underexplored (1–5). Inflammatory Bowel Disease (IBD) is an umbrella term that covers various conditions causing inflammation to the digestive system such as Crohn's Disease (CD) and Ulcerative Colitis (UC), characterised by symptoms of abdominal pain, rectal bleeding, diarrhoea and fatigue (6). Earlier studies have shown that IBD prevalence has been geographically distributed in Northern/Western European, North American and Australian White populations (7–9). Similar trends have also been observed in North American and Western European White populations for Irritable Bowel Syndrome (IBS) (4,5,10), a condition where recurrent abdominal pain/discomfort has an impact on defecation and changes in bowel habits (e.g. disordered defecation, constipation and/or diarrhoea), but without any physiological changes to confirm diagnosis (11,12). Those who have migrated from low prevalence countries (e.g., South Asia) to high prevalence countries (e.g., UK) and their offspring, seem to have higher rates of IBD than the indigenous populations (13–17). Although, it remains tentative of what contributes to this, both genetic susceptibility and environmental influences may contribute to shaping the diverse experiences of ethnic minority populations. Raising important implications for disease management and intervention development for these communities, which need to be better understood (18–21).

Byron et al. (20) framed experiences of chronic bowel illnesses as distinct 'challenges' that increase disease activity, whether physical (e.g., fatigue) and/or psychosocial (e.g., anxiety), and reasoned that individuals adapt to self-manage these daily challenges (e.g., awareness of and being proximal to bathroom facilities), although little is known about the challenges that exist in ethnic minority groups. Dietary changes in these groups can be affected by migration (e.g., accessibility and the availability of traditional diets or ingredients such as fresh fish) and acculturation (e.g., modifications to assimilate with indigenous food choices such as processed food), which may affect the gut microbiome (1,13–15,22). Ethnic minority patients may also receive poor healthcare. Misra et al. (23) found that biological therapy for CD was prescribed significantly less often for South Asians compared to British White patients. Heterogeneity in disease phenotype in ethnic minority groups can be influenced by differential cultural and environmental exposures (e.g., environmental pollutants, smoking and microbial exposure), forming an generational impact (13,23). In the UK, Misra et al. (23) found that most second-generation Indians (aged 15 to 40) had higher age-adjusted incidence of UC compared to White Europeans and Pakistanis, indicating that subcultural differences amongst South Asians themselves needs further consideration, and that heightened genetic susceptibility and environmental triggers may promote the risk of developing UC with a non-colonic phenotype for Indian minority patients. Carr and Mayberry (13) found greater disease severity in second generation South Asians with UC (living in the UK for a minimum of 25 years) compared to first generation migrants and the indigenous population, although the reason for such differences remain unclear.

In this study, we aimed to review literature on ethnic minority peoples' experiences of living with chronic bowel diseases (including IBD), as well as bowel-related symptoms of other chronic diseases.

Methods

Literature search

Search terms were finalised using the Sample, Phenomenon of interest, Design, Evaluation and Research type (SPIDER) framework (see Table 1 and Supplementary Appendix 1) (24). The SPIDER framework (24) is a systematised search strategy tool that facilitates rigour and confidence in the retrieval of studies in reviews, similar to the PICO (25), though the SPIDER framework allows more flexibility for considering various study designs (e.g. qualitative and mixed methods research) than PICO which is suited specifically for quantitative studies (24,25). We searched for qualitative, quantitative, and mixed methods articles on eight electronic databases (CINAHL, PubMed, PsychINFO, Psychology and Behavioural Sciences Collection, Ovid, Embase, Academic Search Primer, and Google Scholar), and manually searched reference lists of frequently cited papers. The search was limited to articles published in the English language, since 2000, reflecting the timeframe for significant developments in medical interventions in conditions such as IBD in the last 20 years (26,27), and the rising incidence of primary bowel conditions in ethnic minority populations (1–3).

Table 1
Search terms based on the SPIDER framework

SPIDER framework	Search terms
Sample (S)	Ethnic* minorit* OR Indigenous OR Native South Asia* OR Bengali OR Bangladesh* OR India* OR Pakistan* OR Sri Lanka* OR Nepal* OR Afghan* OR Black OR Africa* OR Afro Caribbean OR Somali OR Sudan* OR Zimbabwe* OR Turk* OR Arab OR Middle Eastern OR Assyrian OR Kurd OR Iraq* OR Leban* OR Syria* OR Iran* OR Irish OR Gypsy OR Traveller OR Refugee OR Asylum OR Chin* OR Japan* OR Korea* OR Mongolia* OR Latin* OR Puerto Rican OR Mexic* OR Hawai’ian OR Alaska OR Brazil* OR Chile* OR Venezuelan OR Jamaica* OR Cuban OR Hispanic OR Quebec* OR Mohawk OR Inuit OR Metis OR Acadian OR Aboriginal or Melanesian or Maori or Islander OR Filipino OR Indonesia* OR Vietnam* OR Cambodia* OR Burm* OR Malaysia* OR Singapore* OR Timorese OR Laotians OR Europe*
Phenomenon of Interest (PI)	Inflammatory bowel disease OR Crohn OR Ulcerative colitis Bowel function OR bowel dysfunction OR bowel disorder OR bowel cancer Irritable bowel syndrome OR multiple sclerosis Carcinoma OR constipation OR stoma
Design (D)	Interview OR focus group OR survey OR case stud* OR observation OR ethnograph*
Evaluation ®	Experien* OR view* OR opinion* OR attitude* OR feel* OR understanding* OR belief* OR perspectives* OR perception*
Research type ®	Qualitative OR quantitative OR mixed method

Inclusion and exclusion criteria

We conducted a prior scoping review and based our inclusion criteria on this. The search included people of all ages and studies that were: 1) full text original research articles; 2) published in English, since 2000; 3) all ethnic minority participants (as described by authors) or report findings from ethnic minority participants separately from non-minority group participants; 4) resident of countries such as the UK, USA, Australia and New Zealand; 5) any bowel condition or chronic illness causing or leading to bowel symptoms; 6) any qualitative, quantitative or mixed methods designs. We excluded studies that: 1) did not clearly describe participant ethnicity e.g., non-white; 2) the bowel condition or symptom is not explicitly linked to patients’ experiences; 3) experiences of carers, parents, or healthcare professionals; 4) studies on international travellers who are not resident of a country.

Study selection

A PRISMA diagram was used to report the application of the inclusion and exclusion criteria and the selection of final papers for review (Fig. 1).

Data extraction, quality assessment and analysis

All titles, abstracts and full texts were screened by one reviewer (SA); in addition, a random 10% of titles and abstracts were screened by two other reviewers (PDN, OO) and 10% of full texts were screened by three reviewers (PDN, OO, LBD). Disagreements were resolved by discussions and clarification of the inclusion/exclusion criteria as needed. Two recognised critical appraisal tools were used to critique each

included paper and informed data extraction: The Centre for Evidence-Based Management Critical Appraisal (CEBMA) for survey-based studies (28), and the Critical Appraisals Skills Programme (CASP) for qualitative, case-controlled and cohort studies (29). Quality appraisal was reviewed by two reviewers (SA, OO). Due to heterogeneity of designs across studies, a data-driven approach to thematic analysis was taken to identify core themes of patient experiences and this was summarised narratively (30).

Results

Study characteristics

Of the 1347 articles that were originally retrieved, 15 papers were retained for inclusion in the review following screening (Fig. 1). Table 2 illustrates that studies were conducted between 2001 and 2018. Seven studies were conducted in the UK (31–37), seven in the USA (38–44) and one in Malaysia (45). Study design varied and included six case-controlled studies (34,35,39,40,42,44), three survey-based studies (32,33,38,41,43), three qualitative studies (31,36,37), and one cohort study (45); focussing on IBD (31,33–37,39–42,44), IBS (43,45), prostate cancer (including bowel-related side-effects of treatment) (38) and coeliac disease (32). Studies recruited participants from various ethnic minority groups including South Asians, African Americans, Blacks, Hispanics, and Chinese. Three studies that mentioned religious backgrounds comprised of a mixture of religions, where the majority of participants were Muslims (31,36,37). Of studies that mentioned age, seven out of fifteen studies were aimed at adults (over 16) (31,32,34,36,37,39,41). Five studies mentioned that they accommodated for language alongside English, which were mainly South Asian languages (e.g. Hindi, Gujrati, Punjabi, Bengali, Urdu, Mirpuri) (32–34,36), and Spanish (39).

Table 2
Summary of study characteristics

Study, Country	Population	Design	Outcome measures / Instruments	Main results	Strengths / Limitations	Quality rating
	1. disease focus 2. sample size 3. ethnicity 4. age / gender 5. other e.g., language, religion	1. design 2. method 3. sampling method 4. setting	a. psychological health b. quality of life c. physical health d. social health e. miscellaneous			
Alexakis et al. 2015, UK	1. CD (13); UC (6); Other (1) 2. 20 patients 3. South Asian (17; 7 Pakistani, 5 Bangladeshi, 3 Indian, 1 Sri Lankan, 1 Nepal); Mixed white/Asian (1), Black (2) 4. 16–24; male (13); female (7) 5. English; Muslims (13), Christian (2), Hindu/Buddhist (2), Other/Agnostic (2), Mormon (1),	1. qualitative 2. Interviews 3. nil 4. three gastroenterology clinics	e. semi-structured interview measuring experiences	Culturally appropriate IBD information was needed for South Asian parents who had low awareness due to factors such as language barriers. Young people also experienced tensions between effective self-management strategies (e.g., dieting, and religious coping) and cultural norms and practices e.g., spicy food and interruption of prayer for bowel movements. Common experiences across ethnicities included difficulty attaining diagnosis/misdiagnosis and experiencing poor support from primary care services and the educational system	Detailed data; data saturation; pilot study / small sample for generalisation; ethnic mismatch of interviewer and interviewee	CASP 4*
Butterworth et al. 2004, UK	1. coeliac disease 2. 130 patients 3. South Asian (40), White Caucasian (90) 4. over 16; male (27 white Caucasian, 9 South Asian); female (39 white Caucasian, 12 South Asian) 5. various (unspecified)	1. cross-sectional survey-based with case note review 2. questionnaires; cases 3. nil 4. hospital clinic database	c. patients' notes measured small bowel histology and endomysial antibody status at follow-up e. questionnaire measured experiences of living with coeliac and GFD	Compared to White Caucasians, South Asians managed GFD sub-optimally and needed culturally relevant education. South Asians were less likely to attend dietetic clinics, join Coeliac society and they were more dissatisfied with information provided by doctors and dieticians compared to white Caucasians; they were dissatisfied with dietetic advice. There was a correlation between the perception of a strict GFD and normal or near normal small bowel histology and negative endomysial antibody status at follow-up for White Caucasians	Generalisation of findings / low questionnaire response due to language or literacy issues	CEBMA 3*

Study, Country	Population 1. disease focus 2. sample size 3. ethnicity 4. age / gender 5. other e.g., language, religion	Design 1. design 2. method 3. sampling method 4. setting	Outcome measures / Instruments a. psychological health b. quality of life c. physical health d. social health e. miscellaneous	Main results	Strengths / Limitations	Quality rating
Campbell et al. 2004, USA	1. Prostate cancer 2. 40 patients (and their partners) 3. African Americans 4. nil; nil 5. English	1. survey-based 2. questionnaires 3. nil 4. urology speciality clinics; regional tumour registry; the community	a. Self-efficacy for Symptom Control Inventory measured self-efficacy b. EPIC and Physical Function and Mental Health scales of SF-36 measured general QOL	Cancer survivors who had higher self-efficacy had better symptom related QOL related to urinary, bowel and hormonal symptoms and better general QOL e.g., physical functioning and mental health. All patient self-efficacy subscale scores were positively correlated with patient bowel domain scores.	/ zero-order correlations without post hoc analyses; no inferred causation from correlation data; insufficient power for some analysis	CEBMa 3*
Characteristics and main findings of included studies (n = 15) describing study population, design, outcome measures, main findings, strengths/limitations, and quality reported. Abbreviations: CD Crohn's Disease; UC Ulcerative Colitis; IBD Inflammatory Bowel Disease; GFD Gluten Free Diet; QOL Quality of Life; EPIC Expanded Prostate Cancer Index Composite						
Study, Country	Population 1. disease focus 2. sample size 3. ethnicity 4. age / gender 5. other e.g., language, religion	Design 1. design 2. method 3. sampling method 4. setting	Outcome measures / Instruments a. psychological health b. quality of life c. physical health d. social health e. miscellaneous	Main results	Strengths / Limitations	Quality rating
Conroy & Mayberry 2001, UK	1. UC 2. 56 patients 3. South Asians 4. nil; nil 5. English, Hindi, Gujarati, Punjabi	1. survey-based 2. survey; questionnaire and telephone/post contact 3. nil 4. healthcare IBD register	e. postal survey measured initial demand for UC information; follow-up questionnaire measured UC information needs; follow-up telephone and post contact to encourage a good response rate	There was a need for English information on UC to be translated into South Asian languages. Majority of patients provided positive feedback for leaflets offered in English, Hindi, Gujarati, or Punjabi. All patients found the leaflets useful.	Language accommodation / low response rates	CEBMa 3*

Study, Country	Population 1. disease focus 2. sample size 3. ethnicity 4. age / gender 5. other e.g., language, religion	Design 1. design 2. method 3. sampling method 4. setting	Outcome measures / Instruments a. psychological health b. quality of life c. physical health d. social health e. miscellaneous	Main results	Strengths / Limitations	Quality rating
Damas et al. 2018, USA	1. IBD including CD (12) and UC (17) 2. 58 (29 IBD patients, 29 non-IBD control) 3. Hispanics – Cuban, Colombian or Other Latin American 4. over 18; male (11 control, 14 IBD) 5. English, Spanish	1. cross-sectional case-controlled 2. questionnaires 3. nil 4. university-based gastroenterology clinics	e. abbreviated Stephenson Multi-Group Acculturation Scale e. a 24-h diet recall (the ASA-24) e. the Healthy Eating Index (HEI-2010) measured diet quality	Hispanics were mainly bicultural. Most changed their diet after immigration. Patients and controls had poor eating habits, irrespective of the presence of IBD e.g., lower than recommended consumption of total vegetables, legumes, whole grains, and sea plant protein. Compared to controls, IBD patients reported lower intake across all items, particularly total fruit, whole fruit, and total dairy. IBD patients had higher consumption of sodium, refined grains, and empty calories e.g., alcohol, solid fats and added sugars	Representative sample from different countries / small sample size; daily nutrition may differ depending on disease activity	CASP 3*
Farrukh & Mayberry 2016, UK	1. UC 2. 70 patients 3. South Asian (28), White European (42) 4. 16–24; male (16 South Asian, 22 European); female (12 South Asian, 20 European) 5. English and unspecified	1. retrospective case-controlled 2. cases 3. nil 4. three hospitals and community hospital notes	c. record case notes of 1996–1998 and clinical records measured clinical outcomes on surgery and deaths	Surgical and death rates were the same for both South Asians and White Europeans. However, there were differences in provision of care, where South Asians received poorer quality clinical care than Europeans e.g. South Asians were significantly less likely to see a consultant and more likely to be discharged. South Asians were hospitalised more often but had significantly fewer tests than European patients. More screening colonoscopies were offered to Europeans than South Asians, although non-significant.	/ retrospective analysis and 29% of case records have been destroyed, were incomplete or could not be retrieved	CASP 3*
Characteristics and main findings of included studies (n = 15) describing study population, design, outcome measures, main findings, strengths/limitations, and quality reported. Abbreviations: UC Ulcerative Colitis; IBD Inflammatory Bowel Disease; CD Crohn's Disease						

Study, Country	Population 1. disease focus 2. sample size 3. ethnicity 4. age / gender 5. other e.g., language, religion	Design 1. design 2. method 3. sampling method 4. setting	Outcome measures / Instruments a. psychological health b. quality of life c. physical health d. social health e. miscellaneous	Main results	Strengths / Limitations	Quality rating
Study, Country	Population 1. disease focus 2. sample size 3. ethnicity 4. age / gender 5. other e.g., language, religion	Design 1. design 2. method 3. sampling method 4. setting	Outcome measures / Instruments a. psychological health b. quality of life c. physical health d. social health e. miscellaneous	Main results	Strengths / Limitations	Quality rating
Jackson et al. 2007, USA	1. CD 2. 99 patients 3. African American (55); Whites (44) 4. nil; male (50; 26 African American, 24 white); female (49; 29 African American, 20 white) 5. nil	1. retrospective case-controlled 2. interviews; cases; survey 3. nil 4. three gastroenterology clinics	c. telephone interviews; chart reviews; standard evaluations; surveys, measured disease location, surgery, and medication use c. patient statements measured compliance c. clinician assessment measured CD diagnosis	CD may be different in African Americans compared to whites: small bowel disease and small bowel resection was more frequent in white patients. Colonic disease and perirectal fistulae were more frequent in African Americans. White patients sought care for their CD in a clinic setting and reported greater/complete compliance with medical therapy. African Americans more frequently discontinued medical therapy. Both groups felt equally informed about CD, but a greater percentage of White patients felt that their disease was under good control	/ most African Americans were recruited from a hospital with costly medications	CASP 4*

Study, Country	Population 1. disease focus 2. sample size 3. ethnicity 4. age / gender 5. other e.g., language, religion	Design 1. design 2. method 3. sampling method 4. setting	Outcome measures / Instruments a. psychological health b. quality of life c. physical health d. social health e. miscellaneous	Main results	Strengths / Limitations	Quality rating
Goodhand et al. 2012, UK	1. IBD 2. 238 patients 3. Bangladeshi (119); White Caucasian (119) 4. nil; male (72 Bangladeshi; 52 White Caucasian); female (47 Bangladeshi, 67 White Caucasians) 5. nil	1. retrospective case-controlled 2. cases 3. case-based 4. IBD outpatient clinic	c. electronic patient record and IBD database measured demographic data on place of birth and year of migration d. Online Acorn database measured socio-economic data	There were no differences in adjusted age at diagnosis of IBD between Bangladeshis and White Caucasians. Compared to Caucasians, more Bangladeshis were diagnosed with CD than UC. Crohn's phenotype at diagnosis was similar in both groups. But Bangladeshis developed perianal complications and received anti-TNFs earlier and underwent surgery later than White Caucasians. More Bangladeshis with UC had extensive disease, and were anaemic and vitamin D deficient, compared to Caucasians	Bias avoided by matching diagnosis age; accurate phenotyping in single cohort / interpretation and missing data bias; small sample size	CASP 4*
Mukherjee et al. 2015, UK	1. IBD including CD (18) and UC 14 and unclear (1) 2. 33 patients 3. South Asians (20 Indian, 9 Pakistani, 4 Bangladeshi) 4. 18–65; male (13); female (20) 5. Bengali, Gujarati, Hindi, Punjabi, Urdu, Mirpuri, English; Muslim (16), Hindu (9), Sikh (7), no faith (1)	1. qualitative 2. Interviews 3. purposive 4. five gastroenterology clinics	e. Telephone and face-to-face interviews measured experiences, and met and unmet need for support	IBD experience was influenced by South Asian culture (e.g., low awareness meant that the community had difficulty understanding IBD), religion (e.g., difficulties performing ablution and praying). Mostly positive experiences of gastroenterology services, though there was a focus on medical treatment and language barriers. There was an emotional toll (e.g., anxiety) that influenced involvement in activities when symptom free. Practical and emotional support was missing in immediate and extended family. Majority adhered to prescribed medication, but also used complementary and alternative medicine	Representation of South Asians; interviewer living with IBD / time and resources; people over 65 were not recruited; mostly English-speaking participants	CASP 4*
Characteristics and main findings of included studies (n = 15) describing study population, design, outcome measures, main findings, strengths/limitations, and quality reported. Abbreviations: CD Crohn's Disease; IBD Inflammatory Bowel Disease; UC Ulcerative Colitis						

Study, Country	Population 1. disease focus 2. sample size 3. ethnicity 4. age / gender 5. other e.g., language, religion	Design 1. design 2. method 3. sampling method 4. setting	Outcome measures / Instruments a. psychological health b. quality of life c. physical health d. social health e. miscellaneous	Main results	Strengths / Limitations	Quality rating
Study, Country	Population 1. disease focus 2. sample size 3. ethnicity 4. age / gender 5. other e.g., language, religion	Design 1. design 2. method 3. sampling method 4. setting	Outcome measures / Instruments a. psychological health b. quality of life c. physical health d. social health e. miscellaneous	Main results	Strengths / Limitations	Quality rating
Nash, Lloyd & Brooks, 2011, UK	1. CD (13); UC (6); CD and UC (1) 2. 20 patients 3. South Asians (17); Mixed Asian and White (1); Black (2) 4. 17–24; male (13); female (7) 5. English; Islam (13); Christian (2); Agnostic/No religion (2); Hindu (1); Hindu/Buddhist (1); Mormon (1)	1. qualitative 2. interviews 3. opportunity 4. three hospitals	e. telephone and face-to-face interviews measured social inclusion and experiences	Experiences influenced by sociocultural factors such as culture (e.g. conflict of diet choices from low awareness of South Asian parents who have English as a second language), and religion e.g., Islamic religious self-management was beneficial. There was a need for culturally appropriate information for parents, support from schools (e.g., mentoring service, peer support) and healthcare professionals (e.g., communicating information to parents), and family counselling. There were both positive and negative healthcare service encounters. Generic experience across ethnicities included secrecy, social isolation, diagnosis delays/misdiagnosis and disruptions to education	Rich data; data saturation / generalisation to the local population	CASP 4*

Study, Country	Population 1. disease focus 2. sample size 3. ethnicity 4. age / gender 5. other e.g., language, religion	Design 1. design 2. method 3. sampling method 4. setting	Outcome measures / Instruments a. psychological health b. quality of life c. physical health d. social health e. miscellaneous	Main results	Strengths / Limitations	Quality rating
Nguyen et al., 2009, USA	1. IBD including CD and UC 2. 235 patients 3. Black (120); White (115) 4. over 18 / nil 5. English	1. cross-sectional survey-based component of a longitudinal study 2. telephone questionnaire 3. purposeful 4. IBD outpatient clinic	b. SIBDQ measured QOL c. Chapel Hill Index / Simple Colitis Clinical Activity Index measured CD and UC severity c. HBCS measured adherence to medication and appointments d. TIPS	Overall adherence was 65% for both ethnicities. Higher adherence correlated with greater trust-in physician, increasing age and worsening health-related QOL. Adherence was also higher among White patients compared to Black patients. Trust-in-physician, race, and age remained predictors of adherence to medical management after adjustment for employment, income, health insurance, marital and socioeconomic status, and immunomodulator therapy	Adherence measured during asymptomatic periods / all White physicians; potential bias in oversampling older patients; self-reported data	CEBMa 3*
Strauss et al. 2000, USA	1. CD 2. 552 patients 3. Blacks (145); Whites (407) 4. nil; male (29 Black); female (37 white) 5. English	1. case-controlled 2. survey 3. convenience 4. four teaching hospitals and five private practices	b. Medical Outcomes Study Short Form 36 (SF-36) Health Survey measured health status and functioning c. CD activity index (CDAI); the Chapel Hill Index disease activity c. survey on demographic, surgical and hospitalisation data, medication/compliance history, healthcare utilisation/access	Both ethnicities have similar disease presentation and course e.g., age of CD onset, lag in diagnosis time, frequency of gastroenterology-related hospitalisations and surgeries, and medication use. However, there were also differences: Black patients had lower QOL for all categories compared to Whites. White patients were more likely to have health insurance and could identify a regular provider compared to Black patients	Representative sample; good sample size / recall and information bias; generalisability of findings outside tertiary care hospitals	CASP 4*
Characteristics and main findings of included studies (n = 15) describing study population, design, outcome measures, main findings, strengths/limitations, and quality reported. Abbreviations: CD Crohn's Disease; UC Ulcerative Colitis; IBD Inflammatory Bowel Disease; SIBDQ Short Inflammatory Bowel Disease Questionnaire; HBCS Hill-Bone Compliance Scale; TIPS Trust-in-Physician Scale; QOL Quality of Life						

Study, Country	Population 1. disease focus 2. sample size 3. ethnicity 4. age / gender 5. other e.g., language, religion	Design 1. design 2. method 3. sampling method 4. setting	Outcome measures / Instruments a. psychological health b. quality of life c. physical health d. social health e. miscellaneous	Main results	Strengths / Limitations	Quality rating
Study, Country	Population 1. disease focus 2. sample size 3. ethnicity 4. age / gender 5. other e.g., language, religion	Design 1. design 2. method 3. sampling method 4. setting	Outcome measures / Instruments a. psychological health b. quality of life c. physical health d. social health e. miscellaneous	Main results	Strengths / Limitations	Quality rating
Taft, Riehl & Keefer, 2014, USA	1. IBS 2. 243 patients 3. Caucasian (214); non-Hispanic (221); Hispanic (22) <i>[as reported by authors]</i> 4. nil; male (nil); female (209) 5. nil	1. cross-sectional survey-based 2. questionnaires 3. nil 4. one university-based outpatient gastroenterology clinic, online sources and five private practices	a. ISMI; modified for IBS scale for mental illness a. PSS-IBS c. clinical data measured IBS subtype, diagnosis duration, symptom duration prior to diagnosis and symptom frequency	Hispanics reported more perceived stigma for personal relationships and healthcare professionals, compared to non-Hispanics, suggesting that there might be cultural differences in IBS-related stigma experience and highlighting the importance of cultural competence in working with Hispanics with IBS.	/ small sample size; generalisability; not powered to detect differences	CEBMa 3*
Wong et al. 2018, Malaysia	1. IBS 2. 16 patients 3. Chinese (8); Indian (5); Malay (3) 4. median age 67 (13.6); male (6); female (10) 5. nil	1. pilot observational cohort 2. cases and telephone interviews 3. nil 4. dietetic gastroenterology clinic	c. patient records and prospective telephone interviews measured detailed dietary assessments and self-reported symptom record sheet	Compliance with a low FODMAP diet was poor. For patients who complied (complete/partial) with the diet, symptom improvement was reported as: abdominal pain, abdominal bloating/distension and flatulence. Patients with the IBS-D subtype had the greatest improvement in stool consistency	/ representation of older and female Malaysians; subjective assessment of IBS symptoms	CEBMa 4*

Study, Country	Population	Design	Outcome measures / Instruments	Main results	Strengths / Limitations	Quality rating
	1. disease focus 2. sample size 3. ethnicity 4. age / gender 5. other e.g., language, religion	1. design 2. method 3. sampling method 4. setting	a. psychological health b. quality of life c. physical health d. social health e. miscellaneous			
Yarur et al. 2014, USA	1. IBD including CD and UC 2. 142 patients 3. Hispanic (67; 2 Black), non-Hispanic (75; 17 Black) 4. nil; male (74); female (24 Hispanic, 43 non-Hispanic) 5. nil	1. case-controlled 2. cases 3. case-based 4. IBD outpatient clinic	c. inpatient and outpatient medical records measured predictive pre-operative variables and post-operative outcomes	A small increase in post-operative complications in Hispanics compared to non-Hispanics with equal access to medical care and follow-up, but this did not reach significance. Factors independently associated with postoperative complications included diagnosis of UC, preoperative albumin levels, smoking, and use of C20 mg of prednisone	Included a wide range of medical and surgical complications and severity / small sample size; did not account for difference in resource utilisation	CASP 3*
Characteristics and main findings of included studies (n = 15) describing study population, design, outcome measures, main findings, strengths/limitations, and quality reported. Abbreviations: IBS Irritable Bowel Syndrome; PSS-IBS perceived stigma scale for IBS; FODMAP Fermentable Oligosaccharides, Disaccharides, Monosaccharides and Polyols; IBD Inflammatory Bowel Disease; CD Crohn's Disease; UC Ulcerative Colitis						

Overall quality of studies was based on 4 * = criteria met well; 3* = criteria moderately met; 2* = poorly met criteria, 1* = criteria not met

Quality assessment

Based on CASP and CEBMa quality criteria, there were seven good (four star) quality studies (31,35–37,40,42,45), and eight moderately good (three star) quality studies (33,34,38,39,41,43,44).

Narrative synthesis of qualitative and quantitative data produced five broad themes: 1) disease presentation 2) healthcare service 3) medicine adherence 5) psychological health and 5) sociocultural experiences (Fig. 2).

Disease presentation experiences

There were mixed findings on the disease presentation of CD between ethnicities in two US studies (40,42). Jackson & Shaukat (40) reported that although the number of annual flare ups and symptom duration before CD diagnosis did not differ, the nature of CD was different in African Americans compared to Whites, where small bowel disease (84% versus 65%, $p = 0.03$) and small bowel resection (59% versus 16%, $p = 0.01$) were significantly more prevalent in White patients, though colonic disease (89% versus 63%, $p = 0.002$) and perirectal fistulae (58% versus 22%, $p = 0.001$) were significantly higher in African Americans. Straus et al. (42) found that US Black and White patients had similar CD presentations e.g. age of onset. Goodhand et al. (35) reported that 60% of UK Bangladeshi participants had significantly more extensive UC disease compared to 33% of White Caucasians ($p = 0.02$), alongside anaemia ($p < 0.001$) and vitamin D deficiency ($p < 0.05$). In addition, Butterworth et al. (32) found that the presentation of coeliac disease (e.g. the morphological recovery of small bowel mucosa to normal/near normal) between UK White Caucasians and South Asians was similar, though not statistically significant (75% versus 77.8%, $p = ns$ [not reported]).

Experiences of healthcare services

In relation to IBD diagnosis, Goodhand et al. (35) found that UK Bangladeshis were diagnosed with CD significantly more often than with UC, in comparison to White Caucasians ($p < 0.01$), although there were no significant differences in participants age at diagnosis between these ethnicities ($p = 0.52$). Jackson & Shaukat (40) found that there were no significant differences in the setting in which CD was diagnosed for US African American and White patients (clinic: 31% versus 61%; hospital: 47% versus 27%, $p = ns$ [not reported]), the number

of disease flares (3.69 versus 3.1 visits per year), and the duration of symptoms before diagnosis (mean duration of disease 3.5 versus 5.3 years). Alexakis et al. (31) reported that IBD was sometimes misdiagnosed amongst UK South Asian and Black participants as tuberculosis, IBS, stress with diarrhoea or psychosomatic disorders.

Several UK and US studies reported the need for better healthcare services for ethnic minority patients (31,32,34,36,40,42). Attendance at coeliac disease and UC follow-up appointments was more common for White patients compared to other ethnicities in two UK-based studies (32,34). For instance, Farrukh and Mayberry (34) found that South Asians with UC were significantly less likely to be given appointments with a consultant ($z = 1.66$, $p < 0.048$) and more likely to be discharged from hospital follow-up ($z = -2.3$, $p < 0.01$). Majority of the consultants seen by these patients were European and male. Butterworth et al. (32) reported that compared to White Caucasians (author description of ethnicity), South Asians living with coeliac disease were less likely to attend dietician consultations (62.5% versus 21%, $p = 0.005$) and they were significantly dissatisfied with information provided by clinicians and dieticians (8.47% versus 30%, $p = 0.03$) and dietetic advice (6.35% versus 30%, $p = 0.01$); reasons for both these experiences were unclear (32,34). The former study (34) also highlighted that the number of screening colonoscopies offered to White Europeans (43%) was higher compared to South Asians (32%), although this was non-significant ($z = 0.9$, $p = ns$ [not reported]).

Two studies found that IBD-related surgeries were similar across ethnicities (34,42). Farrukh and Mayberry (34) found that surgery ($n = 3$ versus $n = 7$) and death rates ($n = 1$ versus $n = 3$) were similar for UK South Asians and White Europeans. Experiences of post-surgery complications have been reported in two studies (35,44). Goodhand et al. (35) found that compared to White Caucasians, UK Bangladeshis had significantly later surgery (HR [95% CI] 0.4 [0.2, 0.9], $p = 0.03$), developed more perianal complications (HR [95% CI] 8.6 [1.4, 53.1], $p = 0.02$) and received anti-TNFs earlier (HR [95% CI] 3.0 [1.2, 7.7], $p = 0.02$). Additionally, Yarur et al. (44) found increased post-operation complications for US Hispanics and non-Hispanics who had equal access to medical aid and follow-up, but this did not reach significance (OR 1.06 [95% CI] 0.48–2.36, $p = 0.88$). However, postoperative complications were significant factors associated with diagnosis of UC (OR 5.4 [95% CI] 1.67–20.58, $p = 0.004$), preoperative albumin levels (OR 8.2 [95% CI] 2.3–35.5, $p = 0.001$), smoking (OR 15.7 [95% CI] 4.2–72.35, $p = 0.001$), and prednisone use (OR 6.7 [95% CI] 2.15–24.62, $p = 0.001$) (44). Farrukh and Mayberry (34) found that compared to White Europeans, IBD hospitalisations were more common in South Asians ($p = ns$ [not reported]), who also had significantly fewer tests covering wider modalities ($t = 2.1$, $p < 0.02$). Additionally, US White participants were significantly more likely to receive multiple doses of infliximab for CD compared to African Americans (34% versus 11%, $p = 0.005$) (40). Another study (42) found that IBD-related hospitalisations were similar for US Black and White patients (8.3 [SD 15.5] versus 10.2 [SD 17.6], $p = ns$ [not reported]).

Jackson & Shaukat (40) found that US White patients were more likely to seek care for their CD in a clinic setting, whether via primary community physician (1.31 versus 0.21 visits per year, $p = 0.001$) or secondary (hospital) gastroenterologist care (3.2 versus 2.3 visits per year, $p = 0.03$). In two IBD studies with UK South Asians, participants reported experiencing better medical care and expertise in secondary gastroenterology care compared to primary care (31,36), though language barriers still existed (36). Strauss et al. (42) suggested that US ethnic minority groups may have financial constraints in accessing healthcare. White patients were more likely to have health insurance compared to Black patients (92% versus 85%, $p = 0.02$), who were more likely to be receiving Medicaid (17% versus 6%, $p = 0.01$), report unreasonable healthcare delays (mean 1.4 versus 1.3, $p = 0.01$) and have financial difficulties/concerns about affording healthcare (mean 2.8 versus 2.6, $p = 0.03$), which meant delaying appointments (mean 2.8 versus 2.6, $p = 0.02$) and travel to appointment locations (mean 2.8 versus 2.6, $p = 0.01$). The number of CD-related work absences were also more common amongst Black patients, compared to White patients ($p < 0.01$).

Experiences of medicine adherence

Five studies reported experiences of medication use with varied findings (36,37,40–42). Two studies showed that US White participants with IBD had higher medication adherence compared to African American (77% versus 49%, $p = 0.004$) (40), and Black minority patients (HBSC: 15.6 versus 14.0, $p = 0.0002$) (41). In the former study (40), compared to White patients, African Americans significantly discontinued CD medication due to feeling better (27% versus 9%, $p = 0.02$), though they knew that this would cause disease flare ups (25% versus 9%, $p = 0.036$). In the latter study (41), IBD medicine adherence amongst Black patients was significantly related to greater trust in physicians ($R = -0.30$, $p < 0.0001$), increasing age ($R = -0.19$, $p = 0.01$) and worsening health-related quality of life (QOL) ($R = -0.18$, $p = 0.01$). In two other studies, similar medication adherence was reported for the majority of UK South Asians and White Europeans with IBD (36), and between US Black and White participants with CD (92% versus 88%, $p = ns$ [not reported]) (42). However, in the former study (36), many South Asians also used complementary and alternative medication (CAM) alongside prescribed medication (e.g. Ayurvedic medicine and Isabgol), and some consulted faith healers. Another study (37) revealed that UK South Asian Muslims had unclear information on whether they could use medication during the fasting hours of Ramadan, which influenced adherence.

Psychological health experiences

Two UK-based studies found experiences of increased IBD-related anxiety amongst South Asians (33,36). In addition, Mukherjee et al. (36) found that due to the fear of becoming symptomatic, other IBD-related emotional experiences (e.g. depression and feeling low) played a role in inhibiting engagement of social activities during asymptomatic periods. Campbell et al. (38) reported that African American prostate cancer survivors who had higher self-efficacy, also had better symptom-related QOL in relation to urinary (0.59, $p < 0.01$) and bowel function (0.57, $p < 0.01$). Those with higher self-efficacy also had better general health QOL in relation to physical functioning (0.65, $p < 0.01$) and mental health (0.68, $p < 0.01$).

Sociocultural experiences

Awareness of bowel condition and need for culturally relevant information

Low IBD awareness amongst UK South Asians and the wider community was reported by two studies (36,37). Mukherjee et al. (36) found that the South Asian community had difficulty understanding IBD because there was no substitute word for 'Crohn's' in some languages and there were different connotations of the word 'disease' as found in the illness inflammatory bowel disease - for example disease may infer infectious or life-threatening illnesses. Communication about bowel symptoms with other people was perceived as private due to factors such as embarrassment, stigma (e.g., concerns about marriageability and conceiving children) and conflict around cultural expectations e.g., gender roles for a women's ability to manage childcare and housework, and a men's ability to be a provider. In another study (43), compared to non-Hispanics, US Hispanics reported significantly more perceived IBS-related stigma for personal relationships (mean 2.90 versus 1.67, $t[196] = 9.24$, $p = 0.000$) and relationships with healthcare professionals (mean 2.30 versus 1.19, $t[197] = 7.62$, $p = 0.000$).

Mukherjee et al. (36) found South Asians had barriers in using the online Crohn's and Colitis UK (charity) website e.g. language, IT literacy and culturally appropriate venues where participants would not stand out as the only South Asian in a group. Another study (37) reported that younger UK South Asians who were proficient in English were able to access and understand information, but there was little culturally relevant information for parents who had English as a second language. The need for culturally relevant information and education for UK South Asians living with IBD and coeliac disease was identified by four studies (31–33,36). Conroy and Mayberry (33) provided UC information in English, Hindi, Gujarati and Punjabi; they found that all participants found these leaflets useful, and the majority (95%) believed that their doctor needed to provide more support by addressing language problems. The majority of participants (95%) also wanted to learn more about their condition and felt that these information leaflets should be available in GP surgeries (62% of participants), public places (48% of participants), and chemists (38% of participants). Additionally, Jackson & Shaukat (40) reported that both US White and African American participants felt equally informed about CD.

Experiences of dieting

Five out of fifteen studies focussed on experiences of dieting (31,32,37,39,45). Damas et al. (39) found that US Hispanics, of which a majority had adapted to bicultural acculturation (IBD 17 [58.6%]; controls 21 [72.4%], $\chi^2 [3, n = 58] = 3.31$, $p = .35$), changed their diet after migration with no active gastrointestinal symptoms at the time of migration, though this did not reach significance (IBD 72.4%; controls 57.1%, $\chi^2 [1, n = 57] = 1.46$, $p = .23$). Hispanics reported that they developed poor dietary intake (e.g. lower than recommended consumption of vegetables, legumes, whole grains, and sea plant protein), irrespective of whether they had IBD or not (mean IBD 53.8 [SD 13.9]; controls 56.5 [SD 10.5], $t[55] = -.81$, $p = .42$, $d = .22$). Although, IBD patients reported lower intake for total fruit (mean IBD 2.5 [SD 2.3]; controls 3.7 [SD 1.7], $p = 0.02$), whole fruit (mean IBD 2.5 [SD 2.4]; controls 3.8 [SD 2.0], $p = 0.02$), and total dairy (mean IBD 3.1 [SD 3.4]; controls 5.7 [SD 3.5], $p = 0.01$), but higher consumption of sodium (mean IBD 2.0 [SD 2.6]; controls 3.5 [SD 3.1], $t[55] = -1.9$, $p = .06$, $d = .52$), and refined grains (mean IBD 5.5 [SD 3.8]; controls 7.6 [SD 3.3], $t[55] = -2.2$, $p = .03$, $d = .59$). Participants with IBD also met recommended minimal consumption of empty calories such as alcohol, solid fats and added sugars (mean IBD 17.5 [SD 3.9]; controls 13.2 [SD 5.2], $t[55] = 3.56$, $p < .01$, $d = .93$).

Butterworth et al. (32) found that more UK White Caucasians living with coeliac disease significantly reported that they never ingested gluten ($p = 0.04$), or ingested gluten less than once a month compared to the South Asians ($p = 0.03$), suggesting that the management of gluten free diet (GFD) in South Asians may need to be different to White Caucasians, who were more likely to understand food labelling, had access to gluten-free products and were members of the Coeliac Society (charity). A Malaysian study (45) found poor low fermentable oligosaccharides, disaccharides, monosaccharides and polyols (FODMAP) diet in Chinese, Indian and Malays. Those who completely or partially complied with the diet improved IBS-related bowel symptoms e.g., flatulence (87.5%), bloating/distension (70%) and abdominal pain (60%).

Three UK-based studies showed that self-management of diet revolved around avoidance of certain food to reduce symptoms (31,36,37). Although, sometimes there was a conflict and struggle with cultural norms where food was shared (e.g. spicy food, religiously blessed food, family functions and women living with in-laws), which meant that patients had daily practical and emotional issues e.g. anxiety, social exclusion, a sense of loss, social pressure to eat, difficulty getting others to accept their chosen diet and guilt around becoming a burden

(31,36,37). Those participants who compromised on attending social events, sometimes brought separate packed food or had others prepare separate meals for them (31). One study (37) found that little IBD awareness amongst elders also caused tensions in understanding the chosen diet of young people, who found it was difficult to decline requests of elders who encouraged them to eat certain foods that were perceived to be healthy. Conflict led to practical and emotional toll such as hurtful comments about appearance including weight.

Experiences of social support

Social support for South Asians was limited (31,36,37) due to language barriers, lack of culturally relevant information, relying on information from lay sources and for younger patients, difficulties of explaining or censoring information to parents to avoid burdening them e.g. mentioning the chronic nature of IBD (31,37). Some South Asian parents believed that IBD was related to ulcers or poor diet and did not know whether they should inform their child's school (31). Disruption to education was also reported by various ethnic minority groups (31,37), including little integrated IBD understanding and care for young people at schools, which could result in bullying (31).

Experiences of religious self-management

Three studies found that religious coping was important for self-managing IBD, particularly for UK South Asian Muslims. Religious actions had a calming effect (e.g. understanding why participants are experiencing illness and dealing with pain), and believing that IBD was a test from God (31,36,37). Support from religious leaders (e.g. empathy and leaflets on religious guidance during Ramadan) was also noted as beneficial for some Muslims (31). Additionally, managing symptoms was important to participate in Islamic worship (31,36,37); fear of incontinence and anticipated bowel movements created anxieties for Muslims around maintaining ablution (an Islamic ritual that forms the basis of performing various types of worship such as prayer) (31,36), preserving a clean place of worship and avoiding interruptions to prayer (31).

Discussion

Fifteen studies were identified; with a mixture of good and moderately good quality, which explored a range of diverse experiences of ethnic minority patients from UK, US and Malaysia living with IBD, IBS, coeliac disease and bowel symptoms following prostate cancer treatment. Culturally relevant IBD and coeliac disease information/education was needed for UK South Asians due to low awareness, language and literacy barriers, and illness perceptions e.g., private nature of IBD. Muslim South Asians living with IBD used religious self-management to understand illness experiences and had difficulty in managing symptoms (e.g., fear/risk of incontinence) to fulfil religious activities. UK South Asian and Black individuals had problems with IBD diagnosis/misdiagnosis. Ethnic minority populations across countries experienced poor dietary intake (e.g., GFD), cultural conflict in self-managing one's diet (e.g., spicy food), raised IBD-related anxiety and poor-quality healthcare services, particularly primary care in the UK. Mixed findings on the disease presentation experiences showed that the nature of conditions was sometimes similar (e.g., coeliac disease in South Asians), and at times extensive (e.g., UC in Bangladeshis), compared to White populations. Medicine adherence experiences were mixed; some ethnic minority patients had poorer medicine adherence (e.g., US Blacks and African Americans) and some had similar medicine adherence (e.g., US Black), compared to White patients. Some South Asians also used CAM alongside medication.

Low IBD awareness amongst South Asians (and relevant others), generally due to language barriers (36,37), has previously been reported for other chronic illnesses such as cancer and cancer-related services e.g., colorectal screening (46,47), and may indicate generational differences, including older generations for whom English is a second language. Understanding of illnesses may need to be facilitated by cultural relevant information (31–33,36,37), cultivated with linguistic considerations e.g., use and meaning of non-equitable terms – such as 'Crohn's' 'Disease' - in other languages (36). What constitutes as an illness may differ cross-culturally and from Western descriptions (19). The perception, expression and management of an illness and its symptoms (e.g., pain) may be shaped by different cultural influences (e.g. belief systems), psychosocial factors and relationship structures, which healthcare professionals need to be aware of (19,48). IBS for instance, can be conceptualised in terms of emotions (e.g., anxiety, depression) by Indians, hence why there may often be a stigma related to psychological instability in this community. In comparison, Mexicans who value family relationships often attribute emotions (e.g., stress) in relationships to IBS, while Chinese individuals may appraise their connection with their environment; during symptomatic periods, they may express a sense of imbalance with their environment and need to regain this balance through self-management (48).

Using diet to manage symptoms (31,36,37), has been widely reported e.g., avoiding spicy food (20,49) and dining outdoors (49), although this review found that poor understanding of dietary choices of young people with IBD were often not aligned with traditional norms of parents, in-laws or extended family, creating psychological issues (e.g., anxiety) and generational conflict (31,36,37). Dietary changes from migration/accluturation lead to poor meal intakes for Hispanics living with IBD (39), and is supported by previous studies; in Norway, Pakistani and Sri Lankan migrants reduced intake of beans and lentils (50), and Pakistani women increased dairy intake (51). UK South Asians had higher energy and fat intake and lower carbohydrates (52), while Canadian South Asian children had higher intake of fat and

refined sugars, and lower intake of fresh fruit and vegetables compared to their parents and grandparents (15). Literacy issues can have an impact on the efficacy of recommended dietary changes (e.g., understanding food content, acceptability or access to proposed food such as GFD, understanding what constitutes as high and low FODMAP diets) (53–55), as found in this review, South Asians with coeliac disease consumed more gluten compared to White Caucasians since they did not understand food labelling (32).

Stigma related to IBS and IBD were widespread across ethnic minority patients in relation to gender expectations (e.g., conceiving children), and personal relationships (36,43), although such stigma has been reported in other ethnicities (21,56,57). Confidentiality in discussing bowel symptoms were also relevant to Pakistani women with urine incontinence (36,58). Anxieties around IBD symptoms (e.g., fear of incontinence and bowel movements) on managing daily religious duties based on physical purification for Muslim South Asians (31,36,37), has been previously reported with other bowel-related conditions such as IBS (59), colostomy procedures (60,61) and in urinary incontinence (20,58). Since certain bowel symptoms may nullify the state of purification, during symptom flare-ups there may be additional self-management challenges due to the repeated need for purification and needing to be near washing facilities (62); these challenges may be heightened during religious months such as Ramadan, and the Hajj pilgrimage (60,61). Guidance in using medication during Ramadan could be addressed in future interventions (37). Religious actions were noted to have positive impact on experiences of IBD in our review (31,36,37), however other studies revealed that surgical interventions may also reduce QOL (60,61,63). A literature review (61) of stoma patients found that perceptions of symptoms (e.g. uncleanliness) had a negative impact on psychological, religious and spiritual well-being since patients were restricted in fully immersing themselves in religious activities after surgery e.g., participation in congregational prayer in mosques and limited frequency or complete cessation of prayer. Fear of damaging the stoma was mentioned as a contributing factor to ceasing fasting in Ramadan, though medically safe (60,61).

Better healthcare services are needed (31,32,34,36,40,42), and evidence of generally poor health outcomes for ethnic minority groups in the UK and US (31,32,34,35,40,44), suggest the need for a deeper consideration of existing inequalities (20). Earlier studies have also found that US Asians had high unscheduled hospitalisations and African Americans had high emergency department attendance for CD (2). Access disparities in IBD treatment varied across UK regions, where South Asians and Eastern Europeans were significantly less likely to be hospitalised compared to British Whites, while in other areas compared to British Whites, Afro-Caribbeans received significantly less treatment (64). Findings should be taken with the caveat that summarising data across countries may overlook the interactions created between an individual and their environment e.g., socioeconomic factors in accessing medical care may be more relevant to the US, where most ethnic minority patients are likely to be on Medicaid (2), as found in this review (42). In the UK, reasons for disparities are more ambiguous (65). Proposed explanations include discrimination, language preferences, gender choice of healthcare professionals (66), and the lack of awareness of services (65). Inequitable provisions to manage language diversity, as found in gastroenterology services in this review (36), has previously been found to influence communication with healthcare professionals (58,65).

To our knowledge, this has been one of the few studies reviewing literature on the experiences of ethnic minority patients' living with bowel conditions or symptoms. At full text screening, we excluded potentially relevant papers on cancer screening for bowel illnesses since they included participants who may not have pre-existing chronic bowel conditions; however, these papers may have been useful in understanding attitudes of the wider community and needs to be explored. Caution should be taken when applying the findings of the review, as some studies did not account for the diversity within a population e.g., defining ethnicity as 'Blacks' and 'Hispanics', implying that researcher approach to defining ethnicity needs to be reported. One finding may be relevant for an ethnic group in one environment but not others (2). We included two studies that did not fully specify the ethnic group of participants from Hispanic backgrounds (43,44), e.g., Yarur et al. (44) described participants as those from Latin America descent, and Spanish and Portuguese origins, and Caribbean, Black or Other (44). We accepted the search term 'Hispanic' as a baseline descriptor of ethnicity therefore included these studies.

Conclusions

This review has explored experiences of ethnic minority patients living with bowel conditions/symptoms across contexts, but significant gaps remain in unearthing the experience and perspective of individuals who may not be able to speak easily in English. Further qualitative work is needed to understand the cultural sensitivity of such experiences, and to build on extant preliminary data on experiences of psychological health, social support, and religious self-management. There is a need to culturally tailor information for young people who require support from older generations, and to address language and literacy barriers for patients/parents in healthcare services. More research is needed to understand and test the acceptability and feasibility of tailored information. Inequalities in healthcare services, and health outcomes suggest multilevel contextual factors may be at play, specific to the countries in question. A generational and religious lens in understanding contextual experiences of ethnic minority groups may be necessary to understand, for example, cultural conflict in relation to diet. Future research with ethnic minority populations experiencing other bowel-related conditions, such as stoma and anterior resection syndrome following treatment for rectal cancer, is required.

Abbreviations

CAM Complementary and Alternative Medication

CASP Critical Appraisals Skills Programme

CD Crohn's Disease

CEBMA Centre for Evidence-Based Management Critical Appraisal

FODMAP Fermentable Oligosaccharides, Disaccharides, Monosaccharides and Polyols

GFD Gluten Free Diet

IBD Inflammatory Bowel Disease

IBS Irritable Bowel Disease

QOL Quality of Life

SPIDER Sample, Phenomenon of interest, Design, Evaluation and Research type

UC Ulcerative Colitis

Declarations

Ethics approval and consent to participate

Not applicable

Consent for publication

Not applicable

Availability of data and materials

All included papers are published. The data that support the findings of this review are available from the corresponding author upon reasonable request.

Additional file: Ahmed, S. Newton, P. D. Omorogieva, O. Dibley, L. B.

Supplementary Appendix 1: Detailed search strategy. Dataset. FigShare 2021: 10.6084/m9.figshare.13110608

Competing Interests

LBD has received speaker fees from Janssen, AbbVie and Eli-Lilly, and consultancy fees from GL Assessments and Crohn's & Colitis UK. The remaining authors report no conflicts of interest.

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Author' contributions

Development of concept and design of the work (LD, PN), data collection (SA), screening of all articles (SA), second reviewing titles, abstracts and full texts (LD, PN, OO), data extraction (SA, LD, OO), data analysis and interpretation (SA, LD, PN), initial draft of the manuscript (SA), critical revision of the article (SA, LD, PN, OO), and final approval of the version to be published (SA, LD, PN, OO)

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Figures

Figure 1
PRISMA flow diagram

Figure 2

Ethnic minority patients' experiences of chronic bowel conditions or bowel related symptoms

Supplementary Files

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