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Body image dissatisfaction in patients with inflammatory bowel disease: a systematic review

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ABSTRACT

Background and aims Little is known about the relationship between inflammatory bowel disease (IBD) and body image. The aim of this systematic review was to summarise the evidence on body image dissatisfaction in patients with IBD across four areas: (1) body image tools, (2) prevalence, (3) factors associated with body image dissatisfaction in IBD and (4) association between IBD and quality of life.

Methods Two reviewers screened, selected, quality assessed and extracted data from studies in duplicate. EMBASE, MEDLINE, PsycINFO and Cochrane CENTRAL were searched to April 2018. Study design–specific critical appraisal tools were used to assess risk of bias. Narrative analysis was undertaken due to heterogeneity.

Results Fifty-seven studies using a body image tool were included; 31 for prevalence and 16 and 8 for associated factors and association with quality of life, respectively. Studies reported mainly mean or median scores. Evidence suggested female gender, age, fatigue, disease activity and steroid use were associated with increased body image dissatisfaction, which was also associated with decreased quality of life.

Conclusion This is the first systematic review on body image in patients with IBD. The evidence suggests that body image dissatisfaction can negatively impact patients, and certain factors are associated with increased body image dissatisfaction. Greater body image dissatisfaction was also associated with poorer quality of life. However, the methodological and reporting quality of studies was in some cases poor with considerable heterogeneity. Future IBD research should incorporate measurement of body image dissatisfaction using validated tools.

INTRODUCTION

Inflammatory bowel disease (IBD) is associated with a range of debilitating symptoms[1] and affects around 300 000 people in the UK[2], over 1 million in the USA and 2.5 million across Europe.[3] A potentially overlooked issue for patients with IBD is body image dissatisfaction (BID). Body image (BI) is how an individual perceives themselves physically[4] and sufferers have a distorted and negative view of themselves, feeling anxious and uncomfortable about their body. Additionally, negative BI can have a serious impact on health and well-being.[5]

Social media and celebrity attention contribute to pressure to adhere to an 'ideal' body and an obsession with appearance.[6 7] Discontentment with aspects such as body weight, shape, appearance and skin may contribute towards an individual having BID.[8] Studies have shown patients with negative BI are more likely to suffer with depression, anxiety and feel suicidal and BID can impact negatively on relationships[9] and quality of life (QoL).[10]

Various tools have been used in healthcare to measure BI including the Body Image Ideals Questionnaire, the Body Image Scale and the Cash Body Image Disturbance Questionnaire (BIDQ).[11] There are also condition-specific BI tools such as the Body Image Scale (BIS) for IBD.[12]

Both condition-specific symptoms and treatments may contribute to BID in patients with IBD, particularly during periods of active disease rather than remission. Symptoms can include urgent bowel movements, bloating, excess wind, fatigue, skin problems and ulcers. Treatment with steroids can be associated with weight gain, acne and mood swings.[13] Surgeries may also impact on BI due to scarring and implementation of a stoma.[14 15] Those suffering with IBD or BID are at an increased risk of mental health issues[16 17]; this could be worse for patients living with both conditions. Furthermore, most patients with IBD are diagnosed at adolescence,[18] when BI is important. BI is currently not routinely considered in the management of IBD.

No existing or ongoing systematic reviews on BI in IBD have been identified. However, multiple primary studies, mainly cross-sectional in nature, assess BI as an outcome in patients with IBD, with disparate results. A systematic review is therefore warranted to synthesise and clarify the evidence base.

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The following four questions will be addressed:

1. What tools are used to measure BI in patients with IBD and what are their components?
2. What is the prevalence and severity of BID in patients with IBD?
3. What factors are associated with BID in patients with IBD?
4. Is there an association BID in patients with IBD and QoL?

METHODS

This systematic review has been reported according to the Preferred Reporting Items of Systematic Reviews and Meta-Analysis guidelines.[19] A protocol was previously registered (PROSPERO (CRD42018060999)) and submitted for publication and is currently in process.[20] A summary of the methods is reported below. Selection, data extraction and quality assessment were carried out by two independent reviewers with disagreements resolved through discussion or third reviewer.

Search strategy

Bibliographic databases (EMBASE, MEDLINE, PsycINFO, Cochrane CENTRAL) were searched to April 2018 using combinations of index and text terms for IBD and BI (see online supplementary table 1 for MEDLINE strategy). Strategies were adapted for each database and run without date or language restrictions. Trial registries (ClinicalTrials.gov, EU Clinical Trial Register) were searched for ongoing trials and reference lists of included studies were checked.

Screening and selection criteria

Study eligibility was based on the following criteria:

Study design

Any primary study reporting quantitative data.

Population

Patients of any age diagnosed with IBD. At least 50% of population must have IBD unless results are reported separately for subgroups of individuals with IBD.

Tools

Any tool measuring any aspect of BI (including QoL tools that had at least one BI-related domain or question).

Studies were also eligible (for questions 2–4) where they reported any measure of prevalence/frequency and severity of BID in patients with IBD; data on associations between any factor in patients with IBD and BID; or any association between BI and QoL measures in patients with IBD, including associations between two separate domain measures of the same tool.

Exclusion criteria

Case reports, qualitative research and conference abstracts published 3 years before the date of the searches.

Reasons for exclusion were recorded.

Data extraction

A piloted data extraction form was used. Examples of the type of data extracted are shown below.

Study characteristics

Study design, aim and setting, inclusion/exclusion criteria, recruitment methods, follow-up period.

Participant characteristics

Number of patients, age, gender, type of IBD, disease severity and activity, body mass index (BMI), comorbidities, therapy/surgery.

Data for synthesis/analysis

BI measurement tool, components of tools/scales, data on BID (eg, BI scores, prevalence, thresholds for determining BID), factors associated with BI dissatisfaction and strength of association, QoL measures, strength of association between BID and QoL.

Quality assessment

Quality assessment was based on critical appraisal checklists for both prevalence and cross-sectional analytical studies from the Joanna Briggs Institute.[21] Studies solely included for question 1 were not quality assessed as the objective of this question was to compile a list of BI tools.

Important quality items included sample selection, response rate during enrolment in the study, clear inclusion criteria and measurement of outcomes in a valid and reliable way.

Analysis

A narrative synthesis was carried out separately for each question, with key findings tabulated. Substantial heterogeneity relating to populations, tools and settings was apparent in the included studies meaning that meta-analysis was not appropriate. Consistencies and discrepancies in findings between studies were noted and discussed in the context of any likely sources of heterogeneity. Quality assessment findings were used when considering the strength of evidence for the latter three questions.

RESULTS

Database searches identified 587 records and 57[12 14 22–76] studies were included, with some studies eligible for multiple questions (see figure 1 for selection process and reasons for exclusion). All 57 papers reported using BI tools, 31[14 22–26 30 31 33–39 42 47 50 51 53 54 58 60–65 67 69 71 72] reported prevalence or mean/median BI scores, 16[14 23 24 30 34–36 47 54 58 60 61 63 65 67 71] studies presented factors associated with BID and 8[14 22–24 34 61 65 71] studies reported correlations between QoL and BI.

Question 1: what tools are used to measure BI and what are their components?

Of the 57 studies measuring BI, 51 were cross-sectional while the others varied (case–control,[25] prospective cohort,[51 65] case series,[39] randomised controlled trial[64] and non-randomised intervention study[42]). Study

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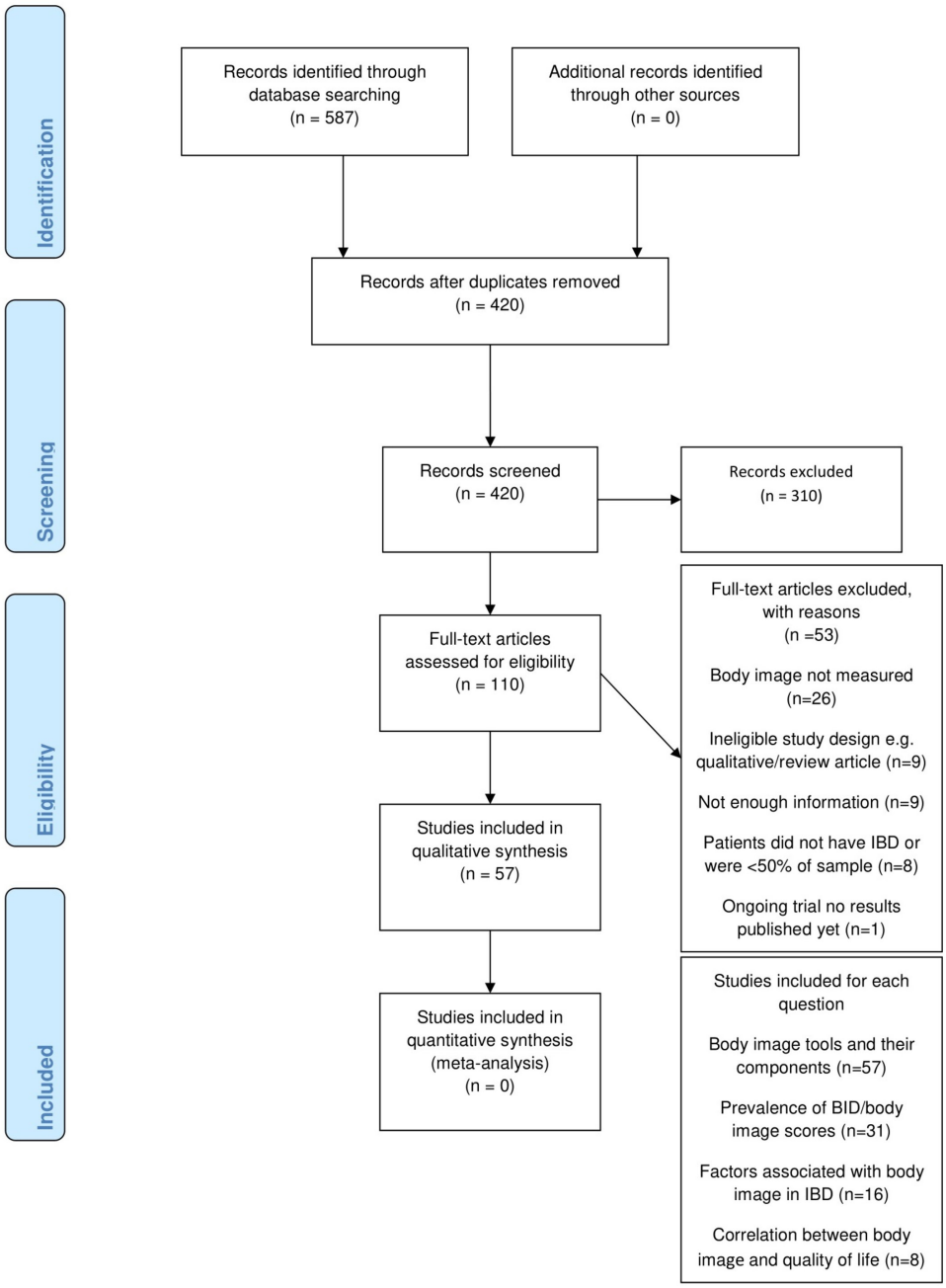

Figure 1 Selection process of records for inclusion/exclusion detailed in a Preferred Reporting Items for Systematic Reviews and Meta-Analyses flowchart. BID, body image dissatisfaction; IBD, inflammatory bowel disease.

populations included adults and children in settings including outpatients, presurgery/postsurgery, summer camps and online registries, from countries across the world. Twenty studies focused on BI as one of the main outcomes, but only six of these studies were non-surgery based.

Fifteen tools were identified (table 1). Seven tools were specifically for BI and eight were QoL tools which included a BI domain or question(s). The most frequently applied tool specific to BI was the Body Image Questionnaire (BIQ) which was used in 14 studies. The BIS was used in five studies and is the only tool validated in an IBD population. IMPACT-III (or earlier IMPACT-II) is a validated QoL questionnaire aimed at adolescents and children with IBD and includes a BI domain. It was used across 18 studies. The remaining 12 tools were used in only one to three studies, respectively.

None of the tools included had a clear cut-off point for defining BID but offered an indication of increasing or decreasing likelihood of dissatisfaction. In some tools, a higher score indicated better BI (BIQ, EORTC, DUX-25). In others, a higher score indicated increased BID (IMPACT, BIS, RFIPC, IBDSI (Inflammatory bowel disease stress index), Body Image Self-Consciousness during Intimacy Scale, BIDQ and ASWAP).

Tools where items had similar themes were grouped to show general focus of BI questions and are shown in table 2.

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Table 1 Tools identified and used across included studies

Measurement tool	Type of tool	Intended target population	Is tool validated?	Scoring	Number of studies tool used in
Body image tools					
ASWAP	Body image	Initially used in patients with scleroderma	Yes but not in patients with IBD	15 items rated on 7-point scale. Questions corresponding to items 4–11 were reverse scored such that higher scores reflect greater dissatisfaction	1
Askevold's Body Image Test	Body image	Unclear	Unclear	Unclear	2
Body Image and Self-Consciousness During Intimacy Scale	Body image and sexual self-consciousness	Women	No	0–75, higher scores poorer body image	1
BIA/BIA-P	Body image	Adults, no specific clinical population	Unclear	Based on body image silhouettes ranging in size. Score=difference between current body size and ideal body size	1
BIQ	Body image	Originally caesarean or appendectomy patients, now patients with IBD	No	5–20, higher score better body image	14
BIS	Body image	Patients with cancer	Yes	0–30, lower score better body image	5
Cash Body Image Disturbance Questionnaire	Body image	Range of clinical groups	Yes but not in patients with IBD	7–35, higher score poorer body image	2
QoL tools with a body image component					
DUX-25	Quality of daily functioning (1 of 4 domains relate to body image)	School-age children	No	Higher scores, better QoL	1
EORTC-QLQ-CR38	QoL questionnaire (3 of 38 items relate to body image)	Patients with cancer	Yes but not in patients with IBD	38 items with four category responses. Functional scales: higher score higher functioning. Symptoms scales: higher score higher level of symptoms	1
EORTC-QLQ-CR29	QoL questionnaire (3 of 29 items relate to body image)	Patients with cancer	Yes but not in patients with IBD	29 items with four category responses Functional scales: higher score higher functioning Symptoms scales: higher score higher level of symptoms	1
IMPACT-III or IMPACT II	Health-related QoL (3 of 35 items relate to body image)	Children and adolescents with IBD	Yes	35–175, higher scores better QoL	18
Inflammatory Bowel Disease Stress Index	Assessing the extent to which IBD has caused alterations in lifestyle (1 of 10 items relate to body image)	Patients with IBD	Unclear	Eight scales with a score of 0–3 (no impact–a great deal of impact)	1
RFIPC	QoL questionnaire (1 item of 25 relate to body image)	Patients with IBD	Yes	0–100, higher score poorer QoL	3
Stoma Quality of Life Scale	Stoma-related (5 items of 19 relate to body image and sexuality)	Patients with stoma	Yes (in ostomy patients)	Five scales, 19 questions. Each scored 1–5 (never–always). Average scores for each scale calculated	3

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Table 1 Continued

Measurement tool	Type of tool	Intended target population	Is tool validated?	Scoring	Number of studies tool used in
The Karolinska Psychodynamic Profile	Assessment of stable modes of mental functioning and character traits (1 subscale and 3 of 18 items relate to body image)	No specific clinical population	Yes	Each subscale is graded from 1 to 3 (most normal–least normal)	2

ASWAP, Adapted Satisfaction with Appearance scale; BI/BIA-P, Body Image Assessment/Body Image Assessment Preadolescent; BIQ, Body Image Questionnaire; BIS, Body Image Scale; DUX-25, Dutch Children's AZL/TNO Quality of Life Questionnaire; EORT-QLQ-CR38/EORT-QLQ-CR29, European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life questionnaire for Colorectal Cancer; IBD, inflammatory bowel disease; IMPACT-II/IMPACT-III, a measure of health-related quality of life in paediatric inflammatory bowel disease; QoL, quality of life; RFIPC, Rating Form of IBD Patient Concerns.

What is the prevalence of BI dissatisfaction in patients with IBD?

Thirty-one studies including a total of 3634 patients reported on prevalence or severity of BID (see table 3 for study characteristics). Seventeen studies[14 22 23 25 30 31 38 42 53 54 58 60 61 65 69 71 72] included both patients with ulcerative colitis (UC) and Crohn's disease (CD). Ages ranged from 2 to 71, and 18 studies[22 30 38 40–42 51–53 57 59–62 69 70 72 75] included only children/adolescents. Fourteen studies[24–26 33–37 39 47 50 63 64 67] included surgery patients and one study included only women.[71]

Only three studies reported prevalence. Brown *et al*[26] found that 21%–34% of patients with UC reported negative impacts on BI using BIQ. McDermott *et al*[14] found that 87% of patients reported some form of concern about an aspect of their BI using the Cash Body Image Disturbance Questionnaire. Muller *et al*[58] reported that 66.8% of patients with IBD stated they had impaired BI based on a researcher-devised questionnaire. The other 28 studies reported mean/median BI scores based on a range of tools.

In studies with populations undergoing surgery, it was found that there was no significant difference in BI scores (using the BIQ) after laparoscopic or open/conventional surgery in patients with IBD.[33–35 63 77] Only one study found BI scores to be significantly improved after laparoscopic surgery compared with conventional surgery in CD.[36].

BI was included as an outcome across 31 studies. All but one study compared results within the included IBD population, for example, UC versus CD, surgery versus no surgery and men versus women. Bel *et al*[23] found that women with IBD with disease in remission scored comparably with women in a healthy population. One longitudinal study by Saha *et al*[65] measured scores over 2 years and found that BI did not change despite improvements in symptoms.

What factors are associated with BID in patients with IBD?

Sixteen studies[14 23 24 30 34–36 47 54 58 60 61 63 65 67 71] totalling 2333 patients with IBD reported the association between various factors and BID (see table 4). Factors included those related to demographics as well as disease and treatment-related characteristics. Ten studies[14 24 34–36 47 63 65 67 71] used a specific BI tool and six[34–36 47 63 67] focused on comparative surgery techniques. Three studies[30 60 61] included a paediatric population; the remaining studies included

Table 2 Body image tools with similar questions grouped into overarching themes

	Components								
Body image tool	Satisfaction with appearance	Attractiveness	Socialising /work	Avoidance of people or tasks	Feeling feminine/ masculine	Effect of disease on body	Scar satisfaction	Satisfaction with body both naked and dressed	Distressing thoughts
BIS	✓	✓	✓		✓	✓		✓	
BIQ	✓	✓			✓	✓	✓	✓	
CBIDQ	✓	✓	✓	✓					✓
ASWAP	✓	✓	✓	✓				✓	

Similar components of tools were grouped into themes shown above. Askevold's Body Image Test (no information in paper or online), Body Image and Self-consciousness during Intimacy Scale (too specific) and the Body Image Assessment (based on figural drawing scales) were not included.
ASWAP, Adapted Satisfaction with Appearance Scale; BIQ, Body Image Questionnaire; BIS, Body Image Scale; CBIDQ, Cash Body Image Disturbance Questionnaire.

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Table 3 . Study characteristics of papers included for questions 2, 3 and 4

Study	Design	Population	Country	Patients (n)	Number of UC/ CD/other	Body image tool	Outcomes	Body image prevalence/ score
Beld *et al* (2010)[24]	Cross-sectional	UC or FAP undergone restorative proctocolectomy IPAA Jan 1992 to Oct 2008	Netherlands	26	UC (16) FAP (10)	BIQ	Mean body image scores (SD)	Men 16.3 (3.1) Women 13.5 (4.1)
Brown *et al* (2015)[26]	Cross-sectional	Patients with UC who had colectomy within the past 10 years, data collected from Nov 2010 to Jul 2011	Canada, Australia, UK	351	All UC	BIQ	Median body image scores (IQR) Prevalence of 'quite a bit' or 'extreme' negative impacts on body image as a result of colectomy	Men 8 (IQR 6–11) Women 11 (IQR 8–14) Age group >50 years 8 (IQR 6–11) Age group <50 years 10 (IQR 7–13) 21%–34% reported negative impacts on body image
Dunker *et al* (1998)[34]	Cross-sectional	Patients with CD undergoing open or laparoscopic resection at Leiden University Medical Centre	Netherlands	34	All CD	BIQ	Mean body image scores	Open 16.4 (10–20) Laparoscopic 18 (13-20) (SD not reported)
Dunker *et al* (2001)[33]	Cross-sectional matched comparison	Patients with UC who underwent laparoscopic-assisted IPAA and matched patients with conventional IPAA	Netherlands	32	UC (28) FAP (4)	BIQ	Mean body image scores (SD)	Laparoscopic 19 (1.3) Conventional 17.9 (SD not reported)
Eshuis *et al* (2008)[35]	Repeated cross-sectional	Patients who underwent ileocolic resection for Crohn's disease from 1995 until 1998 two centres	Netherlands	71 (*medical file analysis*) 61 (*returned questionnaires*)	All CD	BIQ	Mean body image scores (range)	Open 15.63 (6–20) Laparoscopic 16.3 (7–20) (SD not reported)
Eshuis *et al* (2010)	Repeated cross-sectional	Patients with CD who had ileocolic resections between Sep 1999 and Nov 2003	Netherlands	55	All CD	BIQ	Median body image scores (IQR)	Open 18.0 (IQR 16–19) Laparoscopic 19.0 (IQR 17–20)
Giudici *et al* (2017)[39]	Case series (abstract only)	Dec 2014–Dec 2015 Consecutive patients undergoing laparoscopic proctectomy for UC	Italy	10	All UC	Self-designed body image questionnaire	Mean body image score	59 (SD not reported)
Kjaer *et al* (2014)	Cross-sectional	Adult patients treated with laparoscopy-assisted or open IPAA at Odense University Hospital during the period between Oct 2008 and Mar 2012	Denmark	50	UC (44) FAP (4) Other (2)	BIQ	Median body image scores (range)	Laparoscopic 8 (5–18) Open 9.5 (5–20)
Polle *et al* (2007)[63]	Repeated cross-sectional	Patients eligible for an elective proctocolectomy with IPAA for UC or FAP were included in a randomised trial	Netherlands	53	UC (34) FAP (19)	BIQ	Mean body image scores (limited data)	Women open group 15 Laparoscopic group 18 (SD not reported)

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Table 3 Continued

Study	Design	Population	Country	Patients (n)	Number of UC/ CD/other	Body image tool	Outcomes	Body image prevalence/ score
Ponsioen *et al* (2017)[64]	Randomised controlled trial	Eligible patients aged 18–80 years, had active Crohn's disease of the terminal ileum and had not responded to at least 3 months of conventional therapy with glucocorticosteroids, thiopurines or methotrexate. Patients with diseased terminal ileum longer than 40 cm or abdominal abscesses were excluded	Netherlands and UK	70 Infliximab group 73 Laparoscopic ileocaecal resection	All CD	BIQ	Mean body image scores (only given for resection group)	Resection group: Baseline 16 Endpoint 17.8 (SD not reported)
Scarpa *et al* (2009)[67]	Prospective case series	Patients admitted for intestinal surgery for CD May 2006–July 2008	Italy	47	All CD	BIQ	Median body image score (IQR)	5 (5–8)
Eshuis *et al* (2010)[37]	Prospective case series	A consecutive series of patients who had an indication for a laparoscopic ileocolic resection were invited to participate. Patients with CD	Netherlands	10	All CD	BIQ	Median body image scores	Before surgery 17.0 After surgery 19.0
Bengtsson *et al* (2011)[25]	Case–control	Patients with preoperative diagnosis of UC or CD who underwent IPAA	Sweden	101 (*72 controls, 29 study group*)	Controls; UC (60) CD (0) Study group; UC (25) CD (4)	BIS	Median body image scores.	Study group: Men 6.5 Women 10 Control group: Men 1 Women 3
Trindade *et al* (2017)[71]	Cross-sectional	Female participants with ages between 18 and 40 years who had not undergone IBD-related surgery	Portugal	96	UC (58) CD (38)	BIS	Mean body image score (SD)	10.10 (7.73) (SD not reported)
Vlahou *et al* (2008)[72]	Cross-sectional	Adolescents with IBD who attended clinics at two separate hospitals and a camp for children with IBD	USA	44	Breakdown not reported	BSQ (modified version of BIQ) and BIA-P	Mean body image scores (SD)	BSQ: Men 36.45 (4.88) Women 33.52 (7.77) BIA-P: Men 0.41 (0.85) Women 0.77 (0.92)
Grootenhuis (2009)[42]	Non-randomised controlled study	Adolescents with IBD who were under medical care at Emma Children's Hospital AMC and members of Crohn's and Colitis Association Netherlands	Netherlands	18 controls; 22 intervention	Controls CD (11) UC (4) IBDU (3) Intervention CD (17) UC (5) IBDU (0)	DUX-25	Mean body image domain scores (SD)	Intervention: baseline 55.4 (18.6) post intervention 68.9 (17.7) Control: baseline 60.0 (17.4) post intervention 59.0 (20.1)

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Table 3 Continued

Study	Design	Population	Country	Patients (n)	Number of UC/CD/other	Body image tool	Outcomes	Body image prevalence/score
Bel *et al* (2015)[23]	Cross-sectional with controls	18–70 UC or CD	Netherlands	287 (*197 healthy controls*)	UC (132) CD (155)	EORTC-QLQ-CR38	Mean body image domain scores (SD)	Active: Men 5.61 (2.31) Women 6.2 (2.78) Remission: Men 3.82 (1.33) Women 4.58 (1.68)
Shepanksi (2009)	Before and after study	Children attending Camp Guts and Glory in Pennsylvania	USA	61	CD:UC (2:1)	IMPACT II	Mean body image domain scores (SD, for before and after camp)	By age: Age 9–10: Pre 14.6 (4.1) Post 16.4 (3.7) Age 11–12: Pre 11.4 (4.9) Post 13.2 (5.0) Age 13–14: Pre 12.9 (5.2) Post 13.8 (5.9) Age 15–16: Pre 12.3 (5.0) Post 11.2 (5.4)
Abdovic *et al* (2013)[22]	Cross sectional validation study	Children aged 9 years or older with confirmed diagnosis of IBD for more than 6 months from inpatient and outpatient clinics at particular centres.	Croatia	104	UC (30) CD (74)	IMPACT III	Mean body image domain score (SD).	12.03 (1.96)
Chouliaras *et al* (2017)[30]	Cross-sectional	Patients with UC and CD hospitalised or followed in outpatient clinic in Athens	Greece	99	UC (37) CD (62)	IMPACT III	Mean body image domain scores (SD)	Overall 71.5 (17.9) UC 67.3 (22.4) CD 72.6 (19.3) No significant relationship between body image and assessed disease characteristics or prescribed medications
Gallo *et al* (2014)[38]	Cross-sectional	Children between the ages of 8 and 18 years, who had been diagnosed with IBD at least 6 months before, and were being followed at the Paediatric Gastroenterology Service of the Hospital Italiano de Buenos Aires, Argentina, or at the private office of one of the coauthors (MO) and one of their parents	Argentina	27	UC (17) CD (9)	IMPACT III	Mean body image domain score (SD)	76.54 (16.06)
Lee *et al* (2015)[51]	Prospective observational study	Children and young adults less than 22 years of age started on EN or anti-TNF therapy for active CD at Hospital for Sick Children Toronto and Children's Hospital Philadelphia	Canada and USA	90	All CD	IMPACT III	Median body image domain scores (range)	Baseline PEN 71 (54–75) EEN 58 (58–75) TNf 67 (50–83)

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Table 3 Continued

Study	Design	Population	Country	Patients (n)	Number of UC/CD/other	Body image tool	Outcomes	Body image prevalence/score
Mason *et al* (2015)[53]	Prospective observational study	Adolescents >10 years old with confirmed diagnosis of IBD attending gastroenterology clinic at Royal Hospital for Sick Children, Glasgow	Scotland	63	UC/IBDU (18) CD (45)	IMPACT III	Mean body image domain score	7 (SD not reported)
Ogden *et al* (2011)[60]	Cross-sectional validation study	Unclear—children with IBD	UK	97	UC (12) CD (64) IBDU (21)	IMPACT III	Mean body image domain score	63.5 (95% CI 56.5 to 70.6) (SD not reported)
Perrin *et al* (2008)[61]	Cross-sectional	Children aged 8–17 years diagnosed with UC or CD 6 months before the study followed at 1 of 6 paediatric gastroenterology centres. No other chronic conditions	USA	220	UC (59) CD (161)	IMPACT III	Mean body image domain scores (SD)	68.1 (19.6) UC 68.6 (20.8) CD 67.9 (19.2)
McDermott *et al* (2015)[14]	Cross-sectional	Patients with histologically confirmed IBD attending ambulatory clinics in 1 of 2 medical centres between Jul 2011 and Nov 2012	Ireland	330	UC (145) CD (194)	Modified BIS and Cash Body Image Scale (qualitative only)	Median body image score (range) Prevalence	6 (0–27) 13% patients reported no concerns about any aspect of body image
Saha *et al* (2015)[65]	Prospective observational study	Patients with UC, CD or IBDU aged 18 and above enrolled in the Ocean State Crohn's and Colitis Area Registry (OSCCAR) with a minimum of 2 years of follow-up	USA	274	CD (145) UC/IBDU (129)	ASWAP	Mean body image scores (SD)	Baseline: Women 30.1 (14.4) Men 21.2 (8.4) Year 1: Women 28.2 (14.1) Men 24.5 (12.5) Year 2: Women 28.8 (13.2) Men 24.1 (13.5)
Muller *et al* (2010)[58]	Cross-sectional	Patients with IBD aged 18–50 from a database of patients with IBD maintained by the Southern Adelaide IBD Service	Australia	217	UC (85) CD (127) IBDU (5)	No specific tool—range of questions regarding body image and impact of IBD on this	Prevalence (%) of body image dissatisfaction	66.8% of patients reported impaired body image
de Rooy *et al* (2001)[31]	Cross-sectional	Outpatients of the Inflammatory Bowel Disease Centre, Mount Sinai Hospital. Subjects were a convenience sample waiting for a regularly scheduled physician appointment	USA	241	UC (121) CD (120)	RFIPC	'Feelings about body' question mean score (SD)	42.84 (33.97)
Maunder *et al* (1999)[54]	Retrospective analysis	Patients with IBD who had completed the RFIPC and a survey of demographic and disease-related variables in one of three previous studies	Unclear	343	UC (186) CD (157)	RFIPC	'Feelings about body' question mean scores	Women 52.13 (34.8) Men 38.16 (33.83)

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Table 3 Continued

Study	Design	Population	Country	Patients (n)	Number of UC/CD/other	Body image tool	Outcomes	Body image prevalence/score
Kuruvilla *et al* (2012)[50]	Cross-sectional (abstract only)	Consecutive patients who had undergone IPAA or a permanent ileostomy for UC by a single surgeon, presenting for their annual follow-up visit from Jul through Sep 2011, were offered participation in the study. A randomly chosen group of subjects who did not have scheduled appointments during the study period were sent a letter inviting them to participate in the study	USA	59	All UC. IPAA (35); TPC (24)	Stoma Quality of Life Scale	Mean (SD) and median (range) body image/ sexuality domain scores	IPAA: Mean 93.1 (9.7) Median 100 (65–100) TPC: Mean 76.4 (14.6) Median 80 (50–100)

ASWAP, Adapted Satisfaction with Appearance scale; BI/BIA-P, Body Image Assessment/Body Image Assessment-Preadolescent; BIQ, Body Image Questionnaire; BIS, Body Image Scale; BSQ, Body Satisfaction Questionnaire; CD, Crohn's disease; DUX-25, Dutch Children's AZL/TNO Quality of Life Questionnaire; EEN, Exclusive Enteral Nutrition; EORT-QLQ-CR38/EORT-QLQ-CR29, European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life questionnaire for Colorectal Cancer; FAP, familial adenomatous polyposis; IBD, inflammatory bowel disease; IBDU, inflammatory bowel disease unclassified; IMPACT-II/IMPACT-III, a measure of health-related quality of life in paediatric inflammatory bowel disease; IPAA, ileal pouch-anal anastomosis; PEN, partial enteral nutrition; RFIPC, Rating Form of IBD Patient Concerns; TNF, tumour necrosis factor; TPC, total proctocolectomy; UC, ulcerative colitis.

adults. BI was one of the main outcomes in most of these studies and the study by Saha *et al*[65] was the first longitudinal follow-up of BID in IBD according to the authors.

In 6/10 studies,[14 23 54 58 63 65] female gender was found to be significantly associated with increased BID. One study[58] reported the odds of BID was over three times more in women than men (p=0.001), with strong associations reported in the other five studies. Increased disease activity was found to have a significant but moderate positive association in 7/9 studies.[14 23 34 61 65 67 71]

Other factors found to be significantly associated with increased BID included steroid use,[14 60 65 71] age,[14 23] increased BMI,[14 71] smoking[14] and fatigue[23] (table 4). Saha *et al*[65] also found a significant association between extraintestinal manifestations and increased BID, but were the only study to assess this. Laparoscopic surgery was found to be associated with improved body image in 2/6 studies.[36 67] Ileal pouch-anal anastomosis (IPAA) seemed to result in patients being satisfied with their body image in two studies,[24 26] but they lacked a comparative surgery group. One study[50] compared IPAA and ileostomy and found better body image scores in the IPAA group. No significant associations were found between disease subtype and increased BID.

Is there an association between BID and quality of life in patients with IBD?

Eight studies[14 22–24 34 62 65 71] explored a potential association between BID and QoL across a total of 1371 patients, with seven presenting a significant association. Three studies[22 24 61] (table 4) focused on younger populations with the rest including adults only. The majority of studies included populations with both UC and CD while two [24 34] included only one subtype.

Statistically significant weak to moderately strong correlations were present in five studies[22 23 34 61 71] ranging from r=0.34 to r=0.67. Furthermore, McDermott *et al*[14] found that when using the BI scale, there was a significant difference in scores between those with good or poor QoL. Trindade *et al*[71] found that BI was positively correlated with psychological and physical QoL. Saha *et al*[65] found that a one-unit increase in the total ASWAP score (indicating poorer body image) was associated with a 0.62 decrease in QoL score (p<0.0001).

Various QoL tools (see table 1) were used across studies with some using more than one. Four of these questionnaires used (IMPACT II and III, GIQLI (Gastrointestinal Quality of Life Index) and WHOQOL-BREF (World Health Organization Quality of Life Instruments)) contain a question or domain on BI, potentially making them more likely to correlate with BI questionnaires.

Risk of bias

The 31 studies relevant for questions 2–4 were assessed using criteria from the Joanna Briggs Institute critical appraisal tools for analytical cross-sectional and prevalence designs (online supplementary table 2). Only cross-sectional data were relevant for the review. Poor

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Table 4 Most common factors found to be significantly associated with impaired body image in IBD as reported in each study, including associations between reduced body image and reduced QoL

	Study																
Factor	**Abdovic 2013[22]**	**Bel 2015[23]**	**Beld 2010[24]**	**Chouliaras 2017[30]**	**Dunker 1998[34]**	**Eshuis 2008[35]**	**Eshuis 2010**	**Kjaer 2014**	**Maunder 1999[54]**	**McDermott 2015[14]**	**Muller 2010[58]**	**Ogden 2011[60]**	**Perrin 2008[61]**	**Polle 2007[63]**	**Saha 2015[65]**	**Scarpa 2009[67]**	**Trin dade 2017[71]**
Female gender		r=−0.18*	Difference in means p=0.08	Difference in means p>0.10	Difference in scores p=0.18	No significant association			Females significantly worse scores*	p<0.001*	Difference in proportions p=0.0007			Significantly worse scores in open surgery group p=0.004*	p<0.0001*		
Higher disease/ symptom activity		r=0.38*		No significant association	r=0.5*					p<0.001*		p=0.50	p=0.003*		In UC p=0.006* In CD p=0.003*	Multiple regression β=0.426 p=0.006*	Active disease r=0.18 Symptoms r=0.40*
Fatigue		r=0.55*															
Disease subtype				No significant association						p=0.63	Difference in proportions p=0.094		p=0.05		No association found		
Age		r=−0.18*			No significant association					Younger age p<0.001*							r=−0.06
Steroids				No significant association	No significant association					p=0.03*		p=0.05*			p=0.02*		r=0.22*
Smoking										p=0.001*							
Open/ conventional surgery					Difference in scores p=0.2	Difference in means p=0.51	Difference in median p=0.03*	Difference in median p=0.17						No significant differences		Multiple regression (for laparoscopic approach) β=0.331 p=0.036*	
Increased BMI										Women only p<0.001*					No significant association		r=0.25*
Impaired QoL	r=0.52*	r=0.67*	r<0.41		r=0.5*					p<0.001*			r=0.51*		One-unit increase ASWAP score associated with a 0.62 decrease in BDQ (p<0.0001)*		Psychological QoL r=0.56* Physical QoL r=0.50*

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Table 4 Continued

Factor	Study																		
	Abdovic 2013[22]	Bel 2015[23]	Beld 2010[24]	Chouliaras 2017[30]	Dunker 1998[34]	Eshuis 2008[35]	Eshuis 2010	Kjaer 2014	Maunder 1999[54]	McDermott 2015[14]	Muller 2010[58]	Ogden 2011[60]	Perrin 2008[61]	Polle 2007[63]	Saha 2015[65]	Scarpa 2009[67]	Trin dade 2017[71]
With some tools, higher scores indicate better body image/QoL and in others higher scores indicate worse body image/QoL. This may result in both positive and negative correlation coefficients. Where applicable, signs have been flipped for ease of interpretation to clearly show the positive correlation between body image and quality of life.																	
*Significant association found.																	
ASWAP, Adapted Satisfaction with Appearance Scale; BIDQ, Body Image Disturbance Questionnaire; BMI, body mass index; IBD, inflammatory bowel disease; QoL, quality of life.																	

reporting of quality criteria in many studies made quality assessment difficult. Where criteria were reported, the overall quality was variable. Most studies had some areas of low and higher quality. Only one study, McDermott *et al*,[14] was able to demonstrate adequate response rates, validated outcome measurement tools and adjustment for confounders. However, Chouliaras *et al*,[30] Trindade *et al*,[71] Lee *et al*[51] and Bel *et al*[23] adjusted for confounders and used validated outcome measurement tools but lacked adequate response rates.

Twenty studies (64.5%) used an appropriate sample frame with acquisition of patients from outpatient settings, IBD registries or healthcare records. Eighteen studies (58.1%) clearly reported inclusion criteria applied when recruiting participants. Only 12 studies (38.7%) had response rates >75%. Fifteen studies (48.4%) used a tool which had been validated using factor analysis and internal consistency analysis to measure BI. The others used non-validated tools. Twelve studies[14 35 50 51 58 64 65 72] adjusted for potential confounders such as age, gender, BMI and previous surgery often using multiple regression models. Several studies reported limited demographic data. It should also be noted that sample sizes of many of the studies were small and CIs were mostly not presented.

DISCUSSION

Summary of findings

Overall, 15 different tools were used across 57 studies to measure BI in patients with IBD. These included QoL tools incorporating BI questions or domains, BI tools and other adapted questionnaires. None offer a defining threshold for presence or absence of BID, which is not commonly considered as a specific psychological disorder unlike body dysmorphia.

It remains unclear whether patients with IBD suffer with BID more so than the general population as most studies reported mean values with no reference to healthy population values. Three studies estimated a prevalence of a negative BI based on one question, and this varied between 21% and 81%. This wide variation likely reflects the differences in tools and study characteristics. All three studies were based on self-report questionnaires with a wide age range and registry or hospital-based population.

Certain factors including female gender, disease activity and steroid use were consistently found to be significantly associated with increased BID in patients with IBD. There was also a significant association between increasing BID and decreasing QoL reported in eight studies. These findings are consistent with a previous narrative review[78] assessing BID and sexual functioning in patients with IBD.

Strengths and weaknesses of the review

This is the first systematic review assessing BID in an IBD population, and a robust methodology was employed to ensure that bias and errors were minimised. A sensitive search strategy means that it is unlikely that relevant

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studies were missed and over 50 studies have contributed to the evidence base in an area previously unexplored by a systematic review.

The review has some limitations. Some of the extracted data are based on abstracts only where full texts could not be obtained from the authors. This will have resulted in some missing information.

Furthermore, qualitative studies were not included as this was considered beyond the scope of this review. It is likely that there are qualitative studies which could offer a deeper insight into perception of BI in patients with IBD.

Strengths and weaknesses of the evidence

There are some weaknesses within the included evidence. All studies had some areas of high risk of bias or had poorly reported methodological criteria, thus hampering quality assessment. Some studies had very low response rates leading to possible under-representation of certain groups. Few studies adjusted for confounders which could have resulted in overestimates of associations.

A further issue is the lack of healthy control groups. Although it appears that patients with IBD are concerned about BI, it is difficult to determine whether they are affected more than the general population. However, it has been found that children and adolescents with chronic illnesses such as asthma, cystic fibrosis and diabetes do have increased BID compared with healthy peers.[79]

Non-validated tools were often used for measuring BI and the reliability and validity of findings based on these is therefore unknown. There is also still little known about potential changes in BI perception over time.

Findings in context

This review is consistent with findings from the narrative review by Jedel *et al*[78] which found that BI could potentially be a problem in patients with IBD. While surgery has been found to be an important contributing factor in BID in other research,[80] it is unclear how it impacts on patients with IBD. An association between BID and poorer QoL has been highlighted in both.

Females and adolescents are more likely to be concerned with BI and to suffer with BID compared with men and older people.[81–86] While we found inconsistent results surrounding age, IBD is often diagnosed in adolescence when BID could be more of a concern.

In oncology, BI is more widely researched. One study suggested patients with gynaecological cancer suffered with BID which predicted emotional well-being.[87] Another study with patients with advanced cancer suggested BID was associated with depression, anxiety and fatigue.[88] Qualitative research in pregnancy[89] and systematic lupus[90] suggests BI can affect medication compliance and that patients would like more support around dealing with BI issues. This could also be true for patients with IBD.

Finally, a previous systematic review found that children with chronic conditions were more likely to be dissatisfied with their body than healthy peers.[79] Although patients with IBD were not included, patients with similar chronic diseases like diabetes, cancer, asthma and scoliosis were suggesting patients with IBD could be similarly affected.

Implications

This evidence identified in this review suggests an association between BID and poorer QoL as well as finding factors influencing BI in patients with IBD. There were, however, limitations to the evidence in terms of methodological quality and/or reporting. Also, results were difficult to compare across studies. More promisingly, BI is becoming an increasingly assessed outcome, highlighting the need for continued research in this area.

Current research suggests that age, gender, medication and disease activity in IBD may impact on BI. These could be taken into account by clinicians and patients by altering therapy or targeting comorbidities which could have a beneficial effect on BID. Interventions to improve BI could be incorporated into treatment strategies, which may in turn help to improve QoL. A recent systematic review[91] found that stress management, mindfulness and talking therapies may offer small to moderate improvements in BI; however, there is a lack of evidence from good randomised controlled trials.

Future research

Future research should focus on developing a consensus around which validated tool or tools are best suited to measuring BID in an IBD population. While we describe validity of tools such as the Body Image Scale, we have not independently verified this; therefore, we could not recommend a particular tool. Defining thresholds may allow estimation of the prevalence of BID in this population. Establishing reference values in a healthy population would allow for more meaningful interpretation of BID scores across different chronic diseases. Enrolling patients from diagnosis and following them over time would be useful to measure how BI changes with duration, activity of disease and treatment. While more severe IBD symptoms or invasive treatment options may exacerbate BID, BID itself and any associated anxiety or depressive symptoms may in turn exacerbate IBD symptoms,[92 93] and future research should also address this association. If BID is recognised and treated early, it may contribute to preventing worsening disease course. It may also be useful to encourage the use of BI as a patient-reported outcome in future IBD studies. This would increase data on BID and lead to a greater understanding of the condition.

CONCLUSION

In conclusion, the evidence suggests a detrimental effect of IBD on BI, but uncertainty remains due a lack of comparison data from healthy populations.

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Associations of BID with disease-related factors such as steroid treatment, fatigue, disease activity and surgery are apparent and findings suggest a correlation between impaired BI and poorer QoL. These results should be cautiously interpreted due to risk of bias and/or poor reporting of methodological criteria among included studies, and the wide variation between populations, BI tools and scoring systems. Future studies should make use of validated measurement tools and include BI as a main outcome where appropriate.

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