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Psychosocial Experience, Impacts and Management of Fatigue in Young People With Inflammatory Bowel Disease—A Systematic Review

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ABSTRACT

Introduction: Inflammatory bowel diseases (IBD) are chronic conditions frequently accompanied by fatigue. Understanding how young people with IBD experience fatigue, and how psychosocial factors shape its onset, maintenance and management, is essential during this critical developmental period to guide the design of effective, age-appropriate support strategies.

Methods: This mixed-methods systematic review synthesised evidence on fatigue in children and young adults with IBD. Eligibility criteria were defined using the SPIDER framework. Peer-reviewed primary studies involving participants aged $\leq$ 21 years and examining the conceptualisation, measurement, lived experience, psychosocial correlates or management of fatigue were included. Study quality was assessed by two reviewers using the mixed methods appraisal tool with independent dual-review and consensus procedures. Overall methodological quality varied across designs, and findings were interpreted in light of identified limitations in sampling, reporting and methodological rigour.

Results: Thirty-six studies from 10 databases met eligibility criteria. Narrative synthesis identified a lack of a shared definition of fatigue, substantial variability in measurement approaches and reliance on predominantly unidimensional adult-focused tools. Limited research explored lived experience or psychosocial influences in depth. No studies evaluated fatigue-specific interventions, and evidence for indirect behavioural or lifestyle interventions was weak.

Conclusions: It is recommended that a multidimensional conceptualisation of fatigue with standardised developmentally appropriate measurement is adopted, alongside research into psychosocial factors and more in depth qualitative exploration of how young people perceive, interpret and respond to fatigue, to inform theory-driven interventions.

Trial Registration: This review was registered on the International prospective register of systematic reviews database (PROSPERO 2024 CRD42024503531) on 17th January 2024. The registered protocol can be viewed on the PRISMA website (https://www.crd.york.ac.uk/PROSPERO/view/CRD42024503531).

1 | Introduction

Fatigue is one of the most prevalent and burdensome extra-intestinal symptoms of inflammatory bowel disease (IBD), and impacts physical (e.g., weakness and tiredness), cognitive (e.g., poor concentration or reduced cognitive function) and affective (e.g., decreased motivation, low mood and poor energy) functioning [1]. Around 72% of individuals with IBD experience fatigue during periods of active disease, and 47% continue to experience fatigue during remission [2]. These effects can be

Plain Language Summary

Fatigue is one of the most common and challenging extra-intestinal symptoms experienced by people with inflammatory bowel disease (IBD). Although fatigue can have a major impact on everyday life, little is known about how it affects children, adolescents and young adults living with IBD. This systematic review examined research on how fatigue is defined and measured, how young people experience it, the psychological and social factors associated with it and approaches used to support fatigue management.

Thirty-six studies were included. We found that fatigue was defined and measured inconsistently across studies, making it difficult to compare findings. Most measures were developed for adults or for other health conditions rather than specifically for young people with IBD. Only a small number of studies explored young people's experiences of fatigue, and these provided limited insight into how fatigue affects their daily lives. Research examining emotional and social factors was also limited, although some studies reported associations between fatigue and anxiety, depression, self-compassion and physical activity. No studies evaluated interventions specifically designed to reduce fatigue.

Overall, fatigue appears to be a significant and burdensome symptom for young people with IBD, but important gaps remain in understanding its causes, experiences and management. More research is needed to develop effective age-appropriate ways of assessing and treating fatigue in this population.

debilitating: reducing quality of life, impairing daily functioning, reducing symptom acceptance and increasing healthcare utilisation [3, 4].

Approximately 1750 children are diagnosed with IBD in the UK each year [5] and the unique impacts of fatigue in children and young adults with IBD have been identified as a top research priority [6]. Fatigue can exacerbate the unique challenges faced during childhood and adolescence, a period marked by rapid changes in physical, emotional and social functioning [7]. Yet, clinicians often underestimate the significance of fatigue and other extraintestinal and psychosocial aspects of the condition [8].

Although physiological factors contribute to IBD-related fatigue, they do not account fully for its presence or severity, particularly during remission [9]. There is a growing focus on a bio-psychosocial model of fatigue, encompassing the role of psychosocial factors, including social context, mental health and functioning in the onset, maintenance and experience of fatigue [10]. Understanding their role is critical for developing targeted age-appropriate interventions to support young people's symptom management and quality of life. This review addresses this gap by synthesising evidence on the conceptualisation, measurement, lived experience, psychosocial determinants and management approaches for fatigue in young people with IBD. Young people were defined as individuals aged 21 or younger, to capture the transition from childhood through adolescents and into young adulthood [11], a developmental period characterised by substantial biological, psychological, social and educational change, including increasing independence, identity development and educational, occupational and healthcare transitions. These overlapping developmental demands may uniquely shape both the experience and impact of fatigue during this period [12]. This review aimed to synthesise current research on fatigue in young people living with IBD by examining the following criteria:

1. Examining how fatigue is conceptualised and measured.
2. Exploring the lived experience of fatigue.
3. Identifying psychosocial factors involved in the onset and maintenance of fatigue.
4. Examining psychosocial approaches used to support fatigue management.

2 | Methods

This review was co-developed with a patient and public involvement group to ensure the outcomes of importance to those with lived experience were reflected. The review was registered on PROSPERO (CRD42024503531) and followed PRISMA guidelines [13].

2.1 | Search Strategy

Ten electronic databases were searched until 30th September 2025 (Medline; CINAHL; PsycInfo; Psychology and Behavioural Sciences Collection; ScienceDirect; Google Scholar; PubMed; Cochrane Library; IBDJ and Journal of Crohn's and Colitis: Inflammatory Bowel Diseases). Databases were searched for title and abstract separately using search terms focused on fatigue, IBD and adolescents (see Supporting Information S1: Table S1).

2.2 | Inclusion and Exclusion Criteria

Eligibility criteria were defined using the SPIDER framework:

- S (Sample). Young people aged 21 years or younger with inflammatory bowel disease, including Crohn's disease and ulcerative colitis or other forms of colitis, analysed as a distinct cohort.
- PI (Phenomenon of interest). Fatigue.
- D (Design). All peer-reviewed primary study designs reporting empirical original data in English were eligible. Where it was unclear whether data were newly collected or derived from existing databases or recruitment cohorts, studies were retained to avoid unintended exclusion of relevant evidence.
- E (Evaluation). Conceptualisation, measurement, lived experience, psychosocial correlates and management of fatigue.
- R (Research type). Quantitative, qualitative and mixed-methods primary research. Reviews and theoretical or opinion-based articles were excluded.

2.3 | Screening Procedures and Data Extraction

Search results were compiled and duplicates removed. Two reviewers screened abstracts and titles independently to identify eligible articles. Full texts were then assessed for inclusion, with discrepancies resolved through discussion with a third reviewer.

One author extracted information for each research question using standardised forms (see Supporting Information S1: Tables S2 and S3), and a second reviewer independently checked extracted information; disagreements were resolved by a third reviewer.

2.4 | Data Synthesis

As the review included both qualitative and quantitative primary studies and sought to address research questions spanning both experiential and empirical domains, a convergent integrated mixed-methods synthesis was undertaken following JBI methodology [14]. Because of heterogeneity across study designs, statistical pooling was not appropriate, and quantitative findings were, therefore, converted into narrative descriptions before being integrated with qualitative data within each research question domain. Narrative synthesis was used to identify patterns and draw interpretive conclusions across studies, organised according to a priori research questions.

2.5 | Quality Assessment

Methodological quality was assessed using the mixed methods appraisal tool (MMAT) [15], which enables appraisal of qualitative, quantitative and mixed-method designs within a single framework. Two reviewers independently conducted all assessments, with disagreements resolved through discussion and, where necessary, consultation with a third reviewer. Studies were assessed descriptively against design-specific MMAT criteria following completion of the two initial screening questions (see Supporting Information S1: Table S4).

2.6 | Evidence Synthesis

The PRISMA flow diagram (Figure 1) summarises the screening process, which identified 36 included studies, including three identified through backward and forward citation searching.

2.7 | Quality Assessment

Two studies [16, 17] did not pass the screening questions and were excluded from further appraisal due to a lack of clearly defined research questions and insufficient data to address the research aims adequately. Quantitative studies generally met criteria relating to appropriate outcome measurement and completeness of data, but frequently showed limitations in sample representativeness, control of confounding variables and reporting of blinding or adherence. Qualitative studies were appropriate in terms of design and data collection, but lacked clear coherence between data collection, analysis and interpretation. The mixed-methods study demonstrated partial integration of methods, but was limited by insufficient rationale for design choice and limited exploration of divergent findings. Quality appraisal informed interpretation of the findings, with greater caution applied to conclusions given heterogeneity in design and methodological limitations across studies.

2.8 | Characteristics of Included Studies

Most studies were cross-sectional; the remainder were qualitative studies, randomised controlled trials, mixed-methods, longitudinal prospective or non-randomised trials. Fatigue was the primary outcome in 15 studies and the secondary outcome in 21 studies. Although the sample ages ranged from 2 to 21 years, the means suggest most participants were adolescents. Studies reported limited sample diversity, with the majority reporting predominantly male, US-based and White (or did not report race) participants with a diagnosis of Crohn's disease. Where disease activity was reported, most participants were in remission or experiencing mild illness. See further details in Table 1/Supporting Information S1: Table S5.

2.9 | Fatigue Measurement

Thirty-one of the 36 included studies used a quantifiable measure of fatigue (see Supporting Information S1: Table S3). Only two studies explicitly defined fatigue: one [28] briefly described it as low energy or weakness, another [50] defined it as subjectively continuous tiredness marked by lack of energy and exhaustion, which reduces activity and is not relieved by sleep. For most, conceptualisations were inferred from measurement tools, which treated fatigue variably as: a standalone construct (PedsFACIT-F: Paediatric Functional Assessment of Chronic Illness Therapy—Fatigue [51], MFI: Multidimensional Fatigue Inventory [52]); a distinct construct within physical health (PROMIS-Fatigue: Patient-Reported Outcomes Measurement Information System—Fatigue [53]); a component of health-related quality of life (PedsQL-MFS: Paediatric Quality of Life Inventory—Multidimensional Fatigue Scale [54], IMPACT-III [55]); a somatic symptom of depression (CDI: Children's Depression Inventory) or an IBD symptom (patient-identified symptoms). This conceptual variability is reflected in the measurement approaches adopted across studies.

Five studies assessed fatigue using single items embedded within other scales. Two studies [47, 48] used the CDI, in which fatigue is a single somatic item that loads alongside sleep disruption, appetite and pain in factor analysis [56], complicating its independent interpretation. Remaining studies used single fatigue items from the IMPACT-III quality of life questionnaire [16], a priority-ranking questionnaire of IBD symptoms [8] and an unspecified self-report format [38], limiting the interpretation of fatigue as an independent construct.

Twenty-six studies employed established multi-item fatigue instruments (see Table 2). PedsFACIT-F and PROMIS-Fatigue assessed fatigue as a global construct, limiting the depth of assessment given that fatigue is inherently multidimensional, encompassing physical, cognitive and affective components [1]. The PedsQL-MFS captures three domains of fatigue (general, sleep/rest and cognitive) and MFI captures fatigue across five domains (general fatigue, physical fatigue, mental fatigue, reduced activity and reduced motivation), although in some clinical populations an alternative three-factor model is supported [52]. Only three measures (PROMIS-Fatigue, PedsFACIT-F and PedsQL-MFS) were developed for paediatric use, and only one offers age-specific versions (PedsQL-MFS). All four measures were designed for generic chronic conditions not IBD specifically. Reporting often lacked detail, justification for the chosen scale or psychometric information. This is particularly problematic for PROMIS-Fatigue studies, where 10 different item configurations varied in length, selection and administration, leading to inconsistent content coverage.

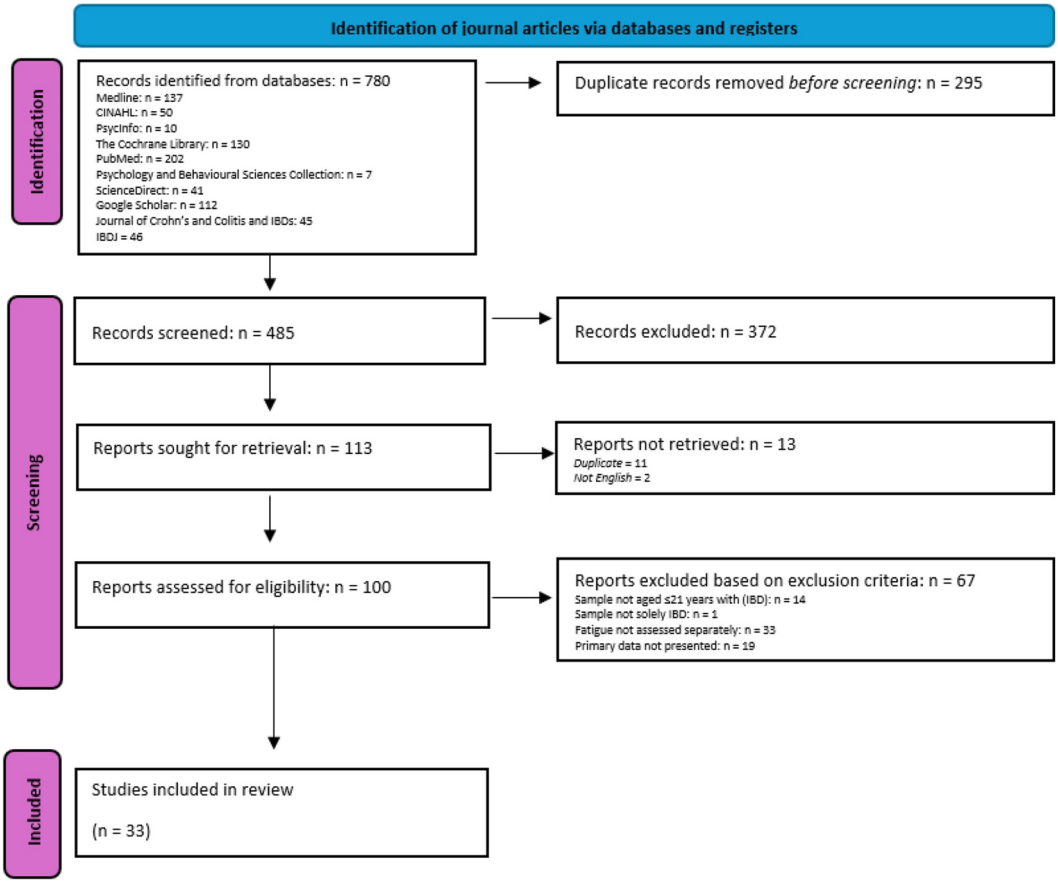

FIGURE 1 | PRISMA flow diagram detailing results of the screening protocols.

Fatigue severity was generally low to moderate across all four multi-item measures, with comparable findings from the single fatigue item within a quality-of-life scale [16]. Where reported, fatigue prevalence varied considerably, reflecting differences in instruments and thresholds used (23% [24] to 56% [28]) in mixed disease activity samples, 65% [36] in a sample where all participants were in remission.

2.10 | Lived Experience

Six studies explored the lived experience of fatigue in young people with IBD, but it was reported as one of several IBD symptoms, rather than being the primary research focus. Four studies collected data through semi-structured interviews [29, 35, 42, 44] and two used surveys [22, 23]. Sample sizes ranged from 10 to 149. Most studies only explored Crohn's disease, and most participants were in remission or had mild illness, which may have influenced the findings. Whilst thematic analysis was commonly employed, it was typically applied in a descriptive or quantified manner (e.g., counting mentions of fatigue, briefly describing symptoms of tiredness or impact on daily activities) rather than exploring underlying processes or lived meaning. Rich qualitative analysis was lacking and none of the studies provided an in-depth experiential account of fatigue in young people with IBD.

Although lacking in depth, these studies provide some inductive insight into the occurrence of fatigue in IBD. Fatigue was consistently reported as a frequent and bothersome symptom across studies. It was the most reported non-gastrointestinal symptom of Crohn's disease by both children (77%) and parents (94%) [42] and was frequently discussed by parents of children with ulcerative colitis (70%) [44]. Fatigue was reported across both remission and active illness [29].

Studies also offered brief descriptions of participants' experiences of fatigue. These descriptions were often depicted as persistent, severe and daily, and using terms associated with tiredness (e.g., *'I was too tired'* [29] and *'I do get tired a lot … Doesn't matter how much I sleep, I'm, like, tired'* [42]). Some participants linked fatigue to more physical aspects (e.g., *'I really feel weak … and lazy'* [44]), showing the association of fatigue to energy and functional capacity.

Studies also highlighted far-reaching impacts of fatigue across multiple life domains, including sleep and attention [29], school participation [29, 35] (e.g., *'I could get a good 10 hours of sleep at night and wake up exhausted… Go to school and fall asleep in class'* [37]), friendships [29] and engaging in normal activities [42] (e.g., *'It's kinda hard for me to go anywhere. I usually have to run off to the bathroom a lot. And I'm always just really tired.'*). Participants also described the subjective experience of difficulties engaging in physical activity [29, 44]. Indeed, fatigue was the most frequently cited IBD-related reason for diminished ability or desire for exercise or sports participation [22] (e.g., participants linked difficulties with physical education and activities to *'fatigue'* and being *'very tired'*). Emotional fatigue associated with the diagnostic procedures was also reported [22]

TABLE 1 | Characteristics of included studies.

Study	Aim	Design	Fatigue outcome	Sample (*n*)	Age (years)	Gender	Predominant race/ethnicity	Recruitment
Arruda et al., 2018 [17]	Determine whether a combined in-person and video-based yoga intervention was a feasible adjunct therapy to medical standard of care for adolescents with IBD	Non-randomised pilot study	Secondary	9	10–21 (M = 14.1)	89% female	Asian/South Asian (56%)	Outpatient clinic/IBD events (US)
Arvanitis et al., 2016 [18]	Assess criterion validity and responsiveness of PROMIS in children with CD	Cross-sectional	Primary	276	9–17 (M = 13)	44% female	White (91%)	CCFA: Internet-based research group (US)
Arvanitis et al., 2021 [19]	Describe transition readiness of young people with IBD and examine its associations with demographic factors, IBD activity and measures of physical, psychological and social health	Cross-sectional	Secondary	480	*Children*: 12–17 (M = 14.5) *Young adults*: *18–20* (M = 18.8)	*Children*: 47% female *Young adults*: 64% female	*Children*: White (89%) *Young adults*: White (91%)	CCFA: Internet-based research group (US)
Azevedo et al., 2024 [20]	Evaluate correlation between PROMIS and current clinical assessment tools	Cross-sectional	Secondary	31	8–17 (M = 15.3)	58% female	NR	Outpatient clinic (Portugal) (same sample in Azevedo et al., 2024 [21]; Azevedo et al., 2025 [22]; Azevedo et al., 2025 [23]; Azevedo et al., 2025 [24])
Azevedo et al., 2025 [25]	Compare parent- and child-reported PROMIS and IMPACT-III scores	Cross-sectional	Primary	31 dyads parent/child	8–17 (M = 15.2)	58% female	NR	Outpatient clinic (Portugal) (same sample in Azevedo et al., 2024; Azevedo et al., 2025 [22]; Azevedo et al., 2025 [23])
Azevedo et al., 2025 [21]	Evaluate responsiveness and clinical utility of PROMIS instruments, compared with standard clinical assessment tools in paediatric CD patients	Longitudinal prospective	Secondary	31	8–17 (M = 15.3)	58% female	NR	Outpatient clinic (Portugal) (same sample in Azevedo et al., 2024 [21]; Azevedo et al., 2025 [22]; Azevedo et al., 2025 [23])
Azevedo et al., 2025 [22]	Explore adolescents' lived experiences with CD and identify factors influencing their motivation for self-management	Qualitative	Secondary	10	12–18 (median = 16)	80% female	NR	Outpatient clinic (Portugal) (A sub-sample from the Azevedo et al., 2024 [21]; Azevedo et al., 2025 [22]; Azevedo et al., 2025 [23])
Beery et al., 2019 [23]	Assess patient-reported exercise participation before and after IBD diagnosis to better understand the impact of disease on this aspect of health	Mixed-methods	Secondary	149	10–18 (M = 16.5)	43% female	NR	Outpatient clinic/infusion centre (US)

(Continues)

TABLE 1 | (Continued)

Study	Aim	Design	Fatigue outcome	Sample (*n*)	Age (years)	Gender	Predominant race/ethnicity	Recruitment
Bevers et al., 2023 [24]	Assess biological and functional factors in young people with mild/moderately active IBD	Cross-sectional	Primary	104	8–18 (M = 14)	49% female	NR	RCT that recruited from 5 outpatient clinics/6 hospitals (Netherlands/Belgium)
Brenner et al., 2020 [26]	Evaluate responsiveness of PROMIS paediatric measures to changes in patient-reported disease activity and disease-specific HRQOL in children with CD	Cross-sectional	Primary	544	9–17 (M = 13.3)	44% female	White (90%)	CCFA: Internet-based research group (US)
Brenner et al., 2021 [27]	Assess construct validity and responsiveness of PROMIS paediatric measures in young people with UC	Cross-sectional	Primary	91	9–17 (M = 13)	57% female	White (88%)	CCFA: Internet-based research group (US)
Cervesi et al., 2013 [8]	Investigate degree of concordance in perception of health concerns between IBD adolescent patients and their physicians	Cross-sectional	Secondary	28	12–19 (median = 16.3)	57% female	NR	Outpatient clinic (Italy)
David et al., 2025 [28]	Explore perspectives of paediatric IBD patients and HCPs on current practices regarding fatigue assessments	Cross-sectional	Primary	43	8–17 (M = 14.2)	54% female	White (79%)	Outpatient clinics within a hospital network (improve care now) (US)
Forrest et al., 2020 [29]	Evaluate content validity of PROMIS paediatric pain interference and fatigue measures in children with CD	Qualitative	Primary	37	8–17 (M = NR)	46% female	White (97%)	Outpatient clinics within a hospital network (improve care now) (US)
Grant et al., 2020 [30]	Develop and validate a new IMPACT-III domain structure in paediatric IBD patients	Cross-sectional	Secondary	296	9–18 (M = 13.4)	43% female	NR	CCFA: Internet-based research group (US)
Greenley et al., 2018 [31]	Extend understanding of risk factors for impairment in sports participation in paediatric IBD	Cross-sectional	Secondary	450	12–17 (M = 14.4)	46% female	White (88%)	CCFA: Internet-based research group (US)
Grossman et al., 2020 [32]	Compare paediatric IBD patient-reported outcomes in black/African American patients with white patients	Cross-sectional	Primary	512	9–18 (M = NR)	45% female	White (95%)	CCFA: Internet-based research group (US)

(Continues)

TABLE 1 | (Continued)

Study	Aim	Design	Fatigue outcome	Sample (*n*)	Age (years)	Gender	Predominant race/ethnicity	Recruitment
Ioan et al., 2023 [33]	Evaluate applicability of a Romanian version of PedsQLTM generic core scale and multidimensional fatigue scale in paediatric IBD patients	Cross-sectional	Primary	13	5–18 (M = 14.2)	61% female	NR	Outpatient clinic (Romania)
Kappelman et al., 2023 [34]	Compare effectiveness and safety of anti-TNF in combination with low-dose, oral methotrexate versus monotherapy	RCT	Secondary	297	> 21 (M = 13.9)	35% female	White (82%)	35 units with a hospital network (improve care now) (US)
Kitchen et al., 2020 [35]	Understand adult and adolescent patients' experiences of CD	Qualitative	Secondary	8	14–17 (M = 15.6)	50% female	White (63%)	Two private group medical practices (US)
Kuzoian et al., 2025 [36]	Determine if sleep tracking and sleep hygiene counselling results in sleep behaviour change and reduced fatigue in patients with IBD	RCT	Primary	66	12–20 (M = 16.5)	47% female	White (68%)	Outpatient clinic (US)
Lucia et al., 2018 [37]	Evaluate relationship between IGF-1, proinflammatory cytokine levels and fatigue in patients with IBD	Cross-sectional	Primary	67	10–16 (median = 13.7)	45% female	White (79%)	IBD clinic (US)
Malik et al., 2012 [38]	Compare HRQOL of proctocolectomy patients with those treated with drugs and determine factors which influence HRQOL in paediatric UC patients	Cross-sectional	Secondary	88	< 18 (M = 15.8)	48% female	NR	Previous inpatient admission (Canada)
Marcus et al., 2009 [39]	Evaluate sleep and daytime tiredness among adolescents with IBD	Cross-sectional	Primary	70	10–17 (M = 14.1)	44% female	White (68%)	5 gastro clinics (Finland)
Miller et al., 2022 [40]	Evaluate whether PROMIS paediatric patient-reported outcome measures serve as valid endpoints in a clinical trial of a chronic paediatric illness	Cross-sectional	Primary	266	8–20 (M = NR)	36% female	White (82%)	RCT (US)
Neiman et al., 2025 [41]	Examine how self-compassion relates to psychosocial health outcomes among young people with IBD	Cross-sectional	Secondary	134	15–25 (M = NR)	58% female	White (63%)	Gastro centre and online (improve care now) (US)

(Continues)

TABLE 1 | (Continued)

Study	Aim	Design	Fatigue outcome	Sample (*n*)	Age (years)	Gender	Predominant race/ethnicity	Recruitment
Newton et al., 2021 [42]	Gain a better understanding of the lived experiences of children with CD	Qualitative	Secondary	31 (+18 parents)	2–17 (M = 11)	50% female	White (61%)	Primary care and gastro clinics (US)
Rampton et al., 2017 [43]	Assess oral ferrous sulphate use difference in haemoglobin response to oral iron treatment of IDA in adolescents compared to adult IBD patients	Non randomised trial	Secondary	45	13–18 (M = 14.9)	49% female	White (53%)	2 gastro clinics (UK)
Randall et al., 2020 [44]	Explore lived experience of UC from a child's perspective	Qualitative	Secondary	12 (+20 parents)	2–11 (M = NR)	35% female	White (60%)	Private group medical practices (US)
Scheffers et al., 2023 [45]	Assess effects of a tailored lifestyle intervention on physical fitness and patient-reported outcomes, clinical disease activity and nutritional status	RCT	Secondary	15	12–16 (M = 15)	40% female	NR	Outpatient service (Netherlands)
Schuchard et al., 2022 [46]	Demonstrate how to interpret PROMIS paediatric patient-reported outcome measure scores for paediatric IBD	Cross-sectional	Secondary	294	8–20 (M = 14)	34% female	White (82%)	Part of a study that recruited from a hospital network (improve care now) (US)
Szigethy et al., 2014 [47]	Identify homogenous groups of youth with IBD who have similar patterns of depressive symptoms and to assess uniquely associated demographic and clinical features, including IBD activity indices, which reflect disease-related inflammation	Cross-sectional	Secondary	226	9–17 (M = 14.3)	53% female	White (82%)	35 study centres (US)
Szigethy et al., 2004 [48]	Assess rates of self-reported depressive symptoms in 102 youths with IBD and examine the relationship between depressive severity and IBD disease factors	Cross-sectional	Secondary	102	11–17 (M = 14.8)	44% female	White (86%)	Recruited from RCT—inpatient and outpatients from two children's hospitals (US)

(Continues)

TABLE 1 | (Continued)

Study	Aim	Design	Fatigue outcome	Sample (*n*)	Age (years)	Gender	Predominant race/ethnicity	Recruitment
Tran et al., 2021 [49]	Test for an association between functional abdominal pain disorder in remission of IBD and past characteristics of IBD	Cross-sectional	Secondary	102	9–17 (M = 15)	44% female	NR	18 paediatric gastroenterology units (inpatient, outpatient and infusion clinics (France)
Turner et al., 2024 [16]	To explore responses to fatigue-related questions in the IMPACT-III questionnaire	Cross-sectional	Primary	80 (44 repeated 8 months later)	9–17 (M = 14.3)	44% female	NR	Volunteer research group (Israel)
Zuo et al., 2024 [50]	Describe prevalence and degree of fatigue in paediatric IBD patients in China	Cross-sectional	Primary	105	6–18 (median = 16)	32% female	NR	Outpatient service (China)

(e.g., *'I hate being in hospital … I feel like just another sick person … drained and very discouraged')*.

2.11 | Psychosocial Factors

None of the included studies primarily examined psychosocial factors associated with fatigue, although several reported relevant secondary findings. Given the limited and indirect nature of this evidence, a broad conceptualisation of psychosocial factors was adopted, synthesising findings from 11 studies relating to social context, mental health and daily functioning (see Table 3).

Seven studies examined social context factors. Sex differences were most frequently explored, with five studies reporting mixed findings: three identified higher fatigue in females [21, 24, 36], whereas two found no sex differences [18, 50]. Age was also inconsistently associated with fatigue, with two studies reporting higher fatigue in older children [18, 50] and three finding no association [20, 21, 24]. Single studies reported lower fatigue in Black/African American participants compared with White participants [32], and lower fatigue in urban compared with rural settings [50], although no association with household income was found. Educational variables showed inconsistent or null associations with fatigue [18, 21, 50].

Four studies examined mental health, with consistent evidence that higher depressive symptoms were associated with greater fatigue [31, 37, 49], and two studies reported associations with anxiety [31, 49]. Higher self-compassion was associated with lower fatigue in one study, independent of demographic and mental health factors [41].

Two studies examined daily functioning using objective measures. Fatigue was associated with lower moderate-to-vigorous physical activity despite similar exercise capacity [24] and was identified as the strongest contributor to perceived impairment in sports participation, independent of disease activity [31].

2.12 | Fatigue Management

No psychosocial interventions set out to directly target fatigue. Three studies indirectly impacted fatigue through targeting behavioural, lifestyle, or psychological factors, albeit as a secondary outcome (see Table 4). Interventions included yoga-based stress management [17], a 'lifestyle programme' combining exercise and diet [45] and sleep behaviour change [36]. These studies were small and likely underpowered. Whilst the yoga-based study did not detect change, modest and inconsistent improvements were found in the other two studies. The lifestyle programme improved parent- but not child-reported fatigue. The only randomised trial found both sleep tracking alone and sleep hygiene counselling were associated with reduced fatigue, although full normalisation was uncommon.

3 | Discussion

This review aimed to synthesise current research on fatigue in young people living with IBD, focusing on its conceptualisation and measurement, lived experience, psychosocial correlates of

TABLE 2 | Multi-item fatigue measures used in reviewed studies.

Fatigue measure		Fatigue severity (*M*)	Scale characteristics	Measured constructs	Population focus
PROMIS-fatigue (paediatric)	Version[a]				
Arruda et al., 2018 [17]	P27	NR	Self-report 4–10 items from 25-item bank 5-point frequency scale (1 'never' to 5 'almost always') T-scores reported: Calculated from raw item responses using algorithms Minimal: < 55 Mild: 55–60 Moderate: 60–70 Severe: > 70 Timescale: 7 days	One of 4 standardised core physical health domains Unidimensional (experience of tiredness/exhaustion/lack of energy & impact on daily functioning) Subjective physical, cognitive, affective fatigue items	General population/ chronic conditions Age 8–17 yrs
Arvanitis et al., 2016 [18]	SF4	48			
Arvanitis et al., 2021 [19]	SF4	47/54			
Azevedo et al., 2024 [20]	SFU	52			
Azevedo et al., 2025 [25]	SF10	52			
Azevedo et al., 2025 [21]	SFU	49/52			
Azevedo et al., 2025 [22]	SFU	47			
Brenner et al., 2020 [26]	SF4/CAT	48			
Brenner et al., 2021 [27]	SF4/CAT	52/56/65			
David et al., 2025 [28]	SF10	59			
Grant et al., 2020 [30]	SF4	47/48			
Greenley et al., 2018 [31]	A4	49			
Grossman et al., 2020 [32]	U	45/49			
Kappelman et al., 2023 [34]	A8	48			
Miller et al., 2022 [40]	SF8	38–50			
Neiman et al., 2025 [41]	P25	NR			
Schuchard et al., 2022 [46]	SF8	NR			

(Continues)

TABLE 2 | (Continued)

Fatigue measure		Fatigue severity (*M*)	Scale characteristics	Measured constructs	Population focus
PedsQL-MFS	Version[b]				
Bevers et al., 2023 [24]	NS	NR	Self/parent report 18-items 5-point frequency scale (0 'never a problem' to 4 'almost always a problem') Reverse-scored/linearly transformed (lower scores = greater fatigue) No cut-off Timescale: 1 month.	Selected from modular health related quality of life inventory Multidimensional (3 domains: General, sleep/rest, cognitive) Subjective physical, cognitive fatigue items	Chronic conditions Age 2–25 yrs Age-specific versions Parent proxy version
Ioan et al., 2023 [33]	YC/C/T	63–69			
Kuzoian et al., 2025 [36]	NS	36–52			
Lucia et al., 2018 [37]	NS	73			
Marcus et al., 2009 [39]	C/T/PP	74			
Scheffers et al., 2023 [45]	C/PP	71			
Zuo et al., 2024 [50]	NS	62			
PedsFACIT-F	Tran et al., 2021 [49]	36/43	Self-report 13-items 5-Point frequency scale (0 'none of the time' to 4 'all of the time') Reverse-scored (lower scores = greater fatigue) No cut-off Timescale: 7 days	Unidimensional (fatigue experience & impact of fatigue on daily activities) Subjective physical fatigue items	Chronic conditions Age 8–18 yrs
MFI	Rampton et al., 2017 [43]	58	Self-report 20 items 5-point frequency scale (1 'yes, i.e. true' to 5 'no, i.e. not true') Low: 20–39 Moderate: 40–60 High: 61–100 Timescale: 2 weeks	Multidimensional (5 domains: General, physical, mental, reduced activity, reduced motivation) Subjective physical, cognitive, affective fatigue items	Chronic conditions Age $\geq$ 18 yrs

[a]PROMIS-Fatigue versions: NS = not specified, SF = short forms (4, 8, 10 or unspecified number of items), A = author-selected versions (4 or 8 items), P = pre-selected profiles (P25 = 4-item; P27 = 6-item), CAT = computer-adaptive test (typically 6–8 items).
[b]PedsQL-Multidimensional Fatigue scale (MFS) versions: NS = not specified, PP = parent-proxy report (all ages; 21-item version for ages 2–4), YC = young children (5–7 years; simplified scale), C = children (8–12 years), T = teenagers (13–18 years), YA = young adults (18–25 years).

onset and maintenance and approaches to fatigue management. Although fatigue is a significant and impactful issue for young people with IBD [1], only 36 studies met the eligibility criteria for this review. Surprisingly, fatigue was rarely the primary focus, despite being consistently reported as a common and burdensome symptom. The evidence base was characterised by conceptual inconsistency, measurement variability, limited qualitative depth and an absence of targeted psychosocial interventions, restricting the extent to which research questions could be addressed.

Few studies explicitly defined fatigue, instead relying on measurement tools reflecting divergent conceptualisations that variably emphasised physical, cognitive and affective components. Consequently, fatigue was inconsistently operationalised as a standalone symptom, an aspect of physical health or quality of life or a symptom of depression. This conceptual conflation, alongside the absence of a shared definition of fatigue, limits the ability to distinguish physiological, psychological and behavioural mechanisms underpinning fatigue.

Fatigue measurement was highly variable, mirroring challenges previously identified in adult IBD populations [57]. Only three measures were developed for paediatric populations, and none were specific to IBD. Although transdiagnostic measures facilitate cross-condition comparisons, fatigue is context-dependent and may manifest differently across conditions [58]. Many studies relied on unidimensional or single-item

TABLE 3 | Psychosocial factors influencing fatigue (comprising social context, mental health and daily functioning).

Study	Psychosocial category	Factors reported	Definition of factors	Assessment of factors	Impact evaluation	Findings relating to fatigue
Arvanitis et al., 2016 [18]	Social context	Age, sex, parental education	Age grouped (9–13 vs. 14–17), sex (M/F), parental education (2th grade, some college, college, graduate school)	Self-reported	Group comparisons	Older children reported significantly higher fatigue than younger children. No significant difference between sex or parental education
Azevedo et al., 2024 [20]	Social context	Age	Age (years)	Self-reported	Correlational	No significant association between age and fatigue
Azevedo et al. 2025 [21]	Social context	Age, sex, educational level	Age (years), sex (M/F), education (international standard classification of education)	Self-reported	Regression	Females had higher baseline fatigue than males. Age was not a significant predictor of fatigue. Education level was not significantly associated with fatigue
Bevers et al., 2023 [24]	Daily functioning + social context	Physical activity patterns + age, sex	Exercise capacity, physical activity over 7 days + sex (M/F), age (years)	6-min walk test, triaxial accelerometer (7 days) + self-reported demographics	Group comparisons/ regression	No difference in exercise capacity. Fatigued patients spent significantly less time in moderate-to-vigorous physical activity. Female sex associated with fatigue in univariable analysis, but was not independently associated after controlling for health-related quality of life and other clinical variables. No age differences
Greenley et al., 2018 [31]	Daily functioning + mental health	Sports participation + anxiety, depression	Perceived impairment in sports; symptoms of anxiety and depression	Sports item on quality of life measure (impact-35) + anxiety and depression measures (PROMIS)	Correlational/regression	Fatigue was the strongest predictor of sports impairment after controlling for disease activity. Fatigue correlated with anxiety and depression
Grossman et al., 2020 [32]	Social context	Race/ethnicity	White versus Black/African American	Self-reported race	Group comparisons	Black/African American patients reported lower fatigue than white patients

(Continues)

TABLE 3 | (Continued)

Study	Psychosocial category	Factors reported	Definition of factors	Assessment of factors	Impact evaluation	Findings relating to fatigue
Kuzoian et al., 2025 [36]	Social context	Sex	Sex (M/F)	Self-reported	Group comparison	Females had significantly higher baseline fatigue than males, but the degree of improvement post sleep-intervention was similar between sexes
Lucia et al., 2018 [37]	Mental health	Depression	Symptoms of depression	Children's depression inventory	Correlational	Higher depressive symptoms strongly correlated with greater fatigue
Neiman et al., 2025 [41]	Mental health	Self-compassion	Multifaceted construct: Self-kindness, common humanity, mindfulness	Self-compassion scale–Short form	Correlational, regression	Higher self-compassion predicted lower fatigue after controlling for age, sex and mental health diagnosis
Tran et al., 2021 [49]	Mental health	Depression, anxiety	Symptoms of depression and anxiety	CDI (depression), SCARED-R (anxiety)	Correlational	In children with functional abdominal pain disorders (FAPD), fatigue is significantly related to anxiety but not depression. In children without FAPD, fatigue is significantly correlated with both anxiety and depression
Zuo et al., 2024 [50]	Social context	Region, age, sex, household income, educational level	Urban versus rural residence; age (years); sex (M/F), per capita annual household income, education: Primary and below/junior high school/ high school and above	Self-reported	Group comparisons + correlation/ regression	Fatigue was lower in urban compared with rural patients; older age was associated with higher fatigue in univariate analysis, whereas sex and household income were not significantly associated with fatigue. Higher educational level was independently associated with greater fatigue

TABLE 4 | Fatigue intervention studies.

Study	Sample	Design	Intervention	Intervention focus	Delivery	Fatigue outcome	Main findings
Arruda et al., 2018 [17]	9 adolescents 10–21 yrs	Non-randomised pilot study	Yoga-based stress management	Not paediatric specific, not IBD specific Physical/psychological intervention	8 weeks: 3 in-person group classes + 3 weekly online sessions. Led by yoga instructor	PROMIS-fatigue (self-report)	Study underpowered.
Scheffers et al., 2023 [45]	15 adolescents 12–16 yrs	Prospective cohort intervention	Tailored healthy lifestyle programme (exercise + dietary advice + CBT if needed)	Paediatric specific, IBD specific Physical intervention (with behavioural/educational components)	12 weeks: 3 physical training sessions + dietician advice + phone follow-up. CBT for unknown number with 'fear of exercise'	PedsQL-MFS (child + parent)	Parent-reported general and sleep/rest fatigue improved; child-reported fatigue unchanged
Kuzoian et al., 2025 [36]	43 adolescents 12–20 yrs	Randomised controlled trial	Sleep behaviour change: Sleep tracking ± hygiene counselling	Paediatric specific, not IBD specific	2 week sleep tracking via logs; psychoeducation (10 min in person + written info)	PedsQL-MFS (self-report)	Both groups improved fatigue; sleep tracking alone more effective; normalisation rare

measures, reducing sensitivity to capture multidimensional fatigue. Consistent with quality appraisal findings, reporting of measure selection and psychometrics was often insufficient, reducing transparency and limiting replicability [59]. This was particularly evident with the PROMIS-Fatigue, where interchangeable item selection and inconsistent reporting hindered interpretation despite the measure being designed to provide standardised comparable scores.

Only six studies qualitatively explored fatigue. Quality appraisal indicated limited analytic coherence, with superficial descriptive summaries or counts of data features rather than deeper engagement or reflexive interpretation, thereby restricting insight into underlying processes or lived meaning [60]. Despite this, fatigue was consistently described as persistent, severe and pervasive, affecting daily functioning, school participation, social relationships, physical activity and emotional wellbeing, mirroring multifaceted impacts reported in adult IBD populations [61, 62]. In adults, rich experiential data reveal how IBD-fatigue reshapes daily routines and social participation, with individuals establishing a 'new normal' through adaptation to persistent fatigue, managing energy strategically and maintaining routines to support wellbeing, often making trade-offs that diminish social engagement [61]. Whether young people experience, respond to and make sense of fatigue similarly remains unknown. This is a particularly important gap given the distinct developmental period of childhood and emerging adulthood characterised by identity formation, increasing independence and complex peer dynamics, during which chronic fatigue can interact with key developmental tasks: reshaping daily routines, influencing peer relationships and altering self-perception [63].

None of the included studies had the primary aim of examining psychosocial factors. Only limited insight can be drawn from psychosocial findings reported as secondary outcomes within 11 studies, which were based on small, methodologically weak and socio-demographically homogeneous samples. Fatigue was higher in young people experiencing depression and anxiety, which may reflect both the elevated risk of comorbidity and the additional burden of living with both IBD and mental health difficulties [64]. However, causal relationships cannot be inferred, and symptom overlap between depression and fatigue complicates interpretation. Self-compassion emerged as a potentially protective factor, consistent with evidence in adults that it reduces psychological distress by countering experiential avoidance, a common maladaptive coping strategy in IBD [65]. Associations between fatigue and social context factors (sex, age, ethnicity, urban–rural residence and socioeconomic status) were mixed, potentially reflecting unequal exposure to modifiable social determinants of health (e.g., social support, community resources and care access) identified in children with long-term health conditions [66]. Fatigue was associated with reduced physical activity, though the relative contributions of physical capacity, motivation and behavioural factors remain unclear.

No psychosocial interventions directly targeting fatigue were identified in this review. Three small, underpowered studies indirectly treated fatigue through yoga, lifestyle and sleep interventions, with modest and inconsistent effects. Evidence from adult IBD populations is also limited, with existing

reviews highlighting methodologically constrained research that offers limited evidence for the efficacy of cognitive-behavioural, solution-focused and psychoeducation approaches [67, 68]. The absence of fatigue-specific interventions may reflect limited understanding of psychosocial drivers of IBD-fatigue, highlighting the need for greater theoretical understanding of the role psychosocial factors play in fatigue.

3.1 | Strengths and Limitations of the Review

This review's strengths include its mixed-methods design, enabling integration of quantitative, qualitative and mixed-methods evidence to provide a comprehensive synthesis of fatigue in young people with IBD across conceptualisation, measurement, lived experience, psychosocial factors and management. The broad SPIDER eligibility framework ensured relevant studies across all these domains were captured. Independent dual screening with consensus procedures reduced selection bias, the MMAT enabled rigorous quality appraisal across all three study designs within a single framework, and patient and public involvement ensured the review addressed outcomes of importance to those with lived experience.

However, heterogeneity in study design, populations and measurement approaches limited interpretation and precluded meta-analysis. Many studies did not primarily focus on fatigue and methodological quality varied, particularly in sampling representativeness and analytical coherence. Many studies were underpowered and relied on cross-sectional designs, limiting the robustness and generalisability of the findings. Samples were predominantly White and US-based, with several recruiting from overlapping cohorts, and most included predominantly Crohn's disease or mild-to-remission samples, limiting generalisability and underscoring the need for more diverse and representative populations. However, as Crohn's disease is more common than ulcerative colitis in young people, this pattern is partly reflective of clinical reality and the need for timely treatment when young people are experiencing severe disease activity makes research participation less feasible [5]. The exclusion of non-English studies further constrained interpretation.

3.2 | Recommendations

The research pathway presented in Figure 2 highlights the progression from current evidence towards key future research priorities. The review highlights fundamental gaps in how fatigue is conceptualised, measured and addressed among young people with IBD, and identifies several priorities for future research.

Conceptualisation and measurement:

- A clear and coherent definition of fatigue should be adopted. This should reflect agreed definitions including the experience of tiredness, weakness or exhaustion that is persistent and overwhelming, leading to a reduced capacity for physical and mental exertion and not relieved fully by rest or sleep.
- Studies should use multidimensional measures, encompassing physical, cognitive and affective components.
- Studies should use psychometrically robust developmentally appropriate measures validated for paediatric IBD populations.
- Further research is needed to evaluate the adaptation and utility of IBD-specific measures, such as the IBD-F [69], for young people.
- Greater transparency in reporting methods is needed in line with open science principles

Lived experience

- Rigorous qualitative research is needed to examine the lived experience of IBD-related fatigue in young people.
- In-depth studies should explore how young people perceive, make sense of and respond to the fluctuating impact of fatigue on everyday life.
- Research should establish whether adolescence presents distinct developmental challenges related to fatigue compared with adulthood.

Psychosocial factors

- Preliminary evidence identifies depression, anxiety, self-compassion and reduced physical activity as potential psychosocial contributors to fatigue; however, further in-depth research is needed to establish the nature of these relationships and their underlying causal mechanisms.
- Future research should adopt theory-driven biopsychosocial frameworks to conduct mechanistic studies of a broader range of psychosocial, behavioural and contextual contributors and protective factors.
- Longitudinal and mixed-methods studies with advanced modelling approaches are needed to examine how psychological, social, behavioural and biological factors interact to influence fatigue trajectories in young people with IBD.

Interventions

- There is an urgent need to develop effective fatigue interventions for young people with IBD, particularly as fatigue often persists despite clinical remission and treatment of biological contributors [2, 10].
- Improved mechanistic understanding of psychosocial processes should inform the development of fatigue-specific interventions tailored to young people.
- Interventions should subsequently be tested in adequately powered methodologically rigorous studies.
- Preliminary evidence supporting sleep and lifestyle interventions warrants further investigation.

4 | Conclusions

This review identified 36 studies examining fatigue in young people with IBD, revealing fundamental gaps in conceptualisation, measurement, lived experience research and psychosocial intervention. Despite its consistent and burdensome impact, fatigue was rarely the primary focus of research. The evidence base was characterised by a lack of a shared definition of fatigue, substantial variability in measurement approaches and reliance on predominantly unidimensional, adult-focused and non-IBD-specific tools. Research exploring lived experiences was limited and largely descriptive, with generally poor methodological

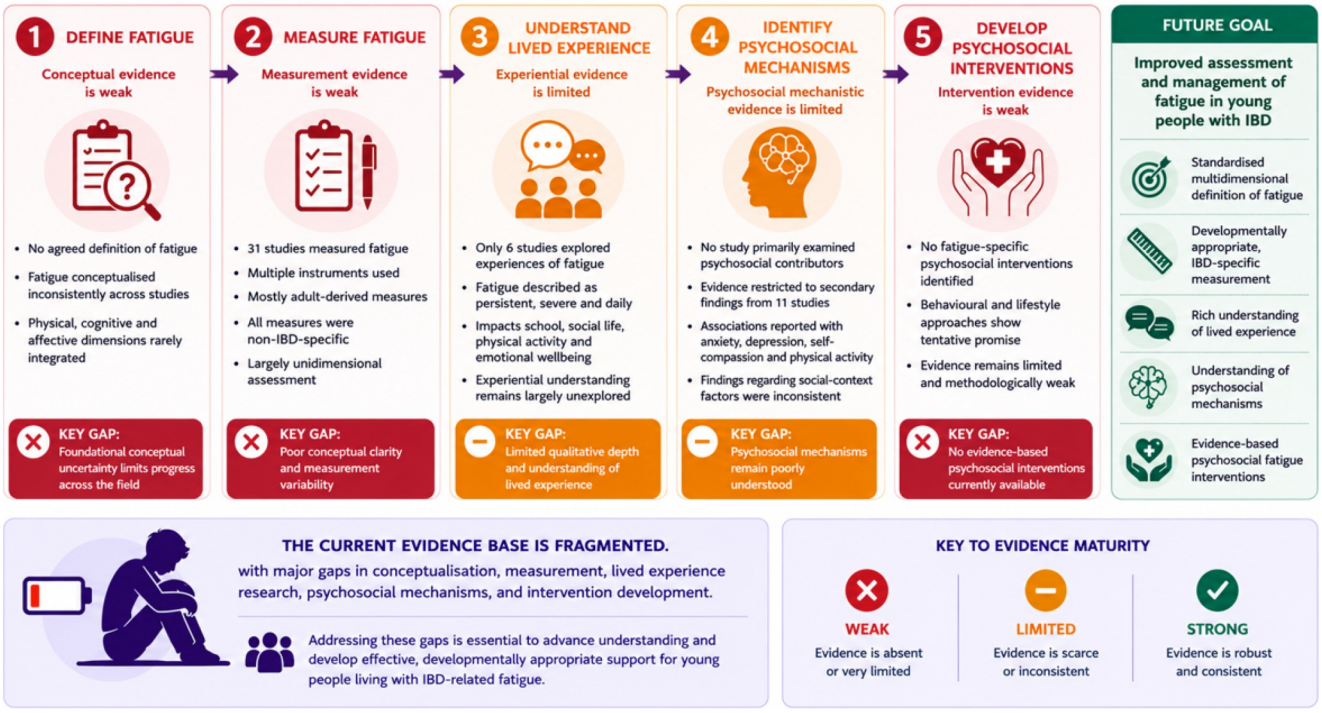

FIGURE 2 | Psychosocial fatigue research pathway in young people with IBD: current evidence gaps and future priorities.

quality. Psychosocial determinants were poorly understood, and no studies evaluated fatigue-specific psychosocial interventions. Evidence supporting indirect behavioural or lifestyle interventions was weak. Progress requires moving beyond fragmented adult-derived approaches towards developmentally grounded models that capture fatigue's multidimensional dynamic nature. Advancing understanding will depend on integrated programmes combining robust measurement, longitudinal and qualitative designs and mechanistic investigation of psychosocial, behavioural and contextual processes. Such work is essential to inform developmentally appropriate interventions, positioning fatigue as a meaningful target. Addressing these gaps offers a key opportunity for health psychology to enhance scientific understanding and clinical support for young people living with IBD-fatigue.

Author Contributions

Kate Muse: conceptualization, methodology, data curation, funding acquisition, writing – original draft, writing – review and editing, project administration, formal analysis, supervision, investigation. **Emma Tickle:** data curation, formal analysis, investigation, writing – original draft, writing – review and editing. **Annabel L. David:** conceptualization, methodology, data curation, formal analysis, investigation, writing – original draft, writing – review and editing. **Suzy Macdonagh:** conceptualization, methodology, writing – review and editing. **Kim Schenke:** data curation, formal analysis, investigation, writing – original draft, writing – review and editing.

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Ethics Statement

The authors have nothing to report.

Consent

The authors have nothing to report.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

Key data is reported in the supplementary materials. Please contact the authors for further data or materials.

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* Indicates inclusion in the systematic review

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Supporting Information

Additional supporting information can be found online in the Supporting Information section.
Supporting Information S1: jcc570060-sup-0001-suppl-data.docx.
Supporting Information S2: jcc570060-sup-0002-suppl-data.docx.