

The impact of depression, anxiety and stress on self-care in inflammatory bowel disease: a systematic review

Simone Amato^a, Alessio Lo Cascio^b, Francesca Iannuzzi^a, Michela Cocco^a, Nicoletta Orgiana^c, Antonio Maria D'Onofrio^d, Giovanni Camardese^{d,e}, Franco Scaldaferrri^{f,g}, Marco Sguanci^h, Daniele Napolitano^f

Tor Vergata University, Rome; La Maddalena Cancer Center, Palermo; CUT - Fondazione Policlinico Gemelli IRCCS, Rome; Università Cattolica del Sacro Cuore, Rome; Link Campus University, Rome; CEMAD - Fondazione Policlinico Gemelli IRCCS, Rome; Università Cattolica Sacro Cuore, Rome; Campus Bio-Medico di Roma University, via Alvaro del Portillo, Rome, Italy

Abstract

Inflammatory bowel disease (IBD), including Crohn's disease and ulcerative colitis, compromises both physical and psychological health. High levels of stress, anxiety, and depression are common yet often overlooked, negatively impacting treatment adherence and self-care. This review examines how psychological factors influence self-care behaviors in IBD and explores strategies to improve disease management. Following PRISMA guidelines and registered on PROSPERO (CRD42024575631), this systematic review applied the PICO model to identify studies involving IBD patients, self-care interventions, and outcomes related to depression, anxiety and stress. A comprehensive search was conducted in PubMed, CINAHL, Web of Science, Scopus, Cochrane Library, APA PsycInfo and Google Scholar (October–December 2024). JBI tools were used to assess risk of bias, and evidence was graded using the framework established by the Oxford Centre for Evidence-Based Medicine. Data extraction and synthesis were performed using structured tables and graphs. IBD patients frequently experience psychological distress that impairs self-care and quality of life. Depression is associated with low self-efficacy and maladaptive coping, while anxiety reduces treatment adherence, particularly in younger patients. Stress contributes to disease management difficulties, reinforcing the need for integrated psychological support. Psychological distress in IBD patients significantly affects self-care behaviors. Incorporating mental health support into standard care may enhance adherence, disease control, and overall well-being.

Keywords Inflammatory bowel disease, self-care, depression, anxiety, stress

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Introduction

Inflammatory bowel disease (IBD), including Crohn's disease (CD) and ulcerative colitis (UC), is a chronic

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Correspondence to: Marco Sguanci, Department of Medicine and Surgery, Research Unit Nursing Science, Università Campus Bio-Medico di Roma, Via Alvaro del Portillo, 21 – 00128, Rome, Italy, e-mail: sguancim@gmail.com

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gastrointestinal condition affecting millions worldwide [1-3]. Characterized by alternating periods of remission and relapse, IBD requires continuous medical management and lifestyle adaptations, making self-care a critical component of disease management [4,5].

Beyond its physical symptoms, IBD significantly affects psychological well-being, with stress, anxiety, and depression being more prevalent in these patients than in the general population [6-8]. Anxiety affects approximately one-third of IBD patients, while depression impacts about one-quarter, with CD patients, particularly women, being at higher risk [9]. Disease activity further exacerbates these psychological conditions [9].

Moreover, psychiatric morbidity has also been reported following surgical interventions for IBD, further emphasizing the complex interplay between disease course and mental health outcomes [10]. Several factors contribute to this psychological burden, including disease unpredictability, prognosis uncertainty, fear of surgery, cancer risk, chronic pain and

fatigue [7,8]. Psychological distress is associated with increased disease activity, higher hospitalization rates and frequent disease flares [11,12]. Additionally, overlapping symptoms, such as fatigue and appetite changes, complicate the diagnosis and management of psychiatric conditions in IBD [13,14]. Stress can further aggravate symptoms by influencing the immune response and intestinal permeability, with higher stress levels correlating with increased disease activity [15].

Self-care plays a fundamental role in managing IBD. According to Riegel's middle-range theory, self-care encompasses 3 key aspects: self-care maintenance (e.g., medication adherence, dietary management, stress reduction), self-care monitoring (symptom tracking), and self-care management (adjusting behaviors or seeking medical attention) [16]. However, many patients face barriers to maintaining effective self-care, [17] and psychological distress further impairs their ability to adhere to treatments, engage in health-promoting behaviors and maintain self-efficacy [18].

Proactive self-care improves disease outcomes, enhances quality of life and reduces healthcare dependency [19]. Addressing mental health is therefore essential to empower patients in managing IBD [18]. Despite growing awareness of the impact of psychological factors on IBD management, a gap remains in our understanding of how anxiety, stress and depression specifically influence self-care behaviors in this population. This systematic review aimed to address this gap by comprehensively examining the existing literature on the relationship between depression, anxiety, stress and self-care practices among patients with IBD.

Materials and methods

Review methodology

This systematic review was conducted and reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Guidelines and following the PRISMA checklist [20] (Supplementary Table 1).

Systematic review protocol registration

The protocol of this systematic review was registered in the International Prospective Register of Systematic Reviews

^aDepartment of Biomedicine and Prevention, Tor Vergata University, Rome (Simone Amato, Francesca Iannuzzi, Michela Cocco); ^bMain Regional Center for Supportive and Palliative Care, La Maddalena Cancer Center, Palermo (Alessio Lo Cascio); ^cCUT - Fondazione Policlinico Gemelli IRCCS, Rome (Nicoletta Orgiana); ^dDipartimento di Neuroscienze, Sezione di Psichiatria, Università Cattolica del Sacro Cuore, Rome (Antonio Maria D'Onofrio, Giovanni Camardese); ^eDepartment of Life Science, Health, and Health Professions, Link Campus University, Rome (Giovanni Camardese); ^fCEMAD - Fondazione Policlinico Gemelli IRCCS, Rome (Franco Scaldaferri, Daniele Napolitano); ^gUniversità Cattolica Sacro Cuore, Rome (Franco Scaldaferri); ^hDepartment of Medicine and Surgery, Research Unit Nursing Science, Campus Bio-Medico di Roma University, via Alvaro del Portillo, Rome (Marco Sguanci), Italy

(PROSPERO) of the National Institute of Health Research (<https://www.crd.york.ac.uk/prospero/>) with the protocol registration number CRD42024575631.

Research question

The present study's search query was formulated using the PICO model [21]. The PICO model serves as a methodology scholars employ to refine a research topic. It revolves around 4 main elements: patient or problem (P), intervention or indicator (I), comparison (C), and outcome (O). This review considered 3 components of the PICO methodology, adopting a PIO. The following aspects were then considered based on the approach: P: patients with inflammatory bowel disease, Crohn's disease, and ulcerative colitis; I: anxiety, stress, and depression O: self-care, self-monitoring, self-management, and self-efficacy.

Search strategy

A comprehensive and systematic literature search was conducted in scientific databases between October and December 2024, including PubMed, CINAHL (Cumulative Index to Nursing and Allied Health Literature), Web of Science, Scopus, Cochrane Library and APA PsycInfo. To achieve a targeted and precise search, we used a combination of specific keywords and MeSH terms (medical subject headings), using the keywords: "inflammatory bowel diseases", "Crohn's disease", "ulcerative colitis", "self-care", "self-monitoring", "self-management", "self-efficacy", "anxiety", "stress", "depression" and their variants, appropriately combined by Boolean operators. A manual search was conducted in Google Scholar to retrieve additional records in the gray literature. In the screening phase, 2 expert reviewers (MC and FI) independently assessed all titles and abstracts extracted from the electronic database searches. Using Rayyan software (<https://rayyan.com/>), duplicates and irrelevant records were systematically eliminated, and a third reviewer (DN) was consulted to facilitate consensus. Full-text articles were obtained for those potentially relevant in the initial screening. Each of these was subjected to rigorous independent assessment by the reviewers (MC and FI), in line with the predetermined eligibility criteria. In situations where consensus was difficult, dialogues were initiated between the primary reviewers. In case of non-agreement, the decision was referred to the third reviewer (DN), previously uninvolved, to ensure an unbiased decision-making process. Search strategy is showed in Supplementary Table 2.

Inclusion criteria

We included studies that explored how depression, anxiety and stress influence self-care in patients with IBD. Conversely, we excluded research that involved individuals without IBD, that addressed behaviors not related to self-care, or that did not highlight the presence of depressive, anxious, or stressful symptoms.

Evaluation of the risk of bias and methodological quality of studies

The risk of bias and methodological quality of the included articles was initially assessed by 2 reviewers (MC and FI). Conflicts were resolved by a third review author (DN). To rigorously evaluate the methodological quality and relevance of the selected studies, we used the JBI Critical Appraisal Tools (JBI: JBI Critical Appraisal Tools. Accessed from <https://jbi.global/critical-appraisal-tools> on 15/12/2024). These tools, recognized for their accuracy in evaluating various research designs, provided a structured framework to discern the reliability and applicability of each study. By using these tools, we ensured that only the most robust and relevant studies were incorporated into our systematic review [22]. High-quality studies were identified based on a previous meta-analysis [23], in which studies with a JBI score of more than 70% were classified as high quality, those with a score between 69.9% and 50% as medium quality, and those with a score below 50% as low quality. The result of this evaluation is reported in Supplementary Tables 3-5.

Assessment of evidence certainty

This systematic review evaluated the strength of evidence using the framework established by the Oxford Centre for Evidence-Based Medicine (OCEBM) in 2011 [24], as noted in Supplementary Table 6. According to this system, studies are categorized into 5 levels of evidence, depending on their research design and quality. Studies of the highest quality, such as systematic reviews of randomized controlled trials (RCTs) and well-conducted RCTs, are classified as level 1. In contrast, research primarily relying on expert opinion or lacking empirical backing is placed at level 5. Intermediate-quality studies, such as less rigorous RCTs, cohort studies, and methodologies including case series or case-control studies, are assigned to levels 2, 3 and 4. Additionally, the evidence level of certain studies may be adjusted up or down based on factors such as methodological rigor, result precision, and relevance to the topic being examined [25].

Data extraction

Data from the selected articles were extracted and reported in the tables: Author, Year, Country, Type of study, Interventions, Depression, Anxiety, Stress and Influence of Psychosocial Factors on Self-Care (Table 1).

Data synthesis

The articles incorporated in this review were systematically categorized according to the behaviors adopted. Each type of behavior was first reported through a narrative summary and then in specific tables and graphs.

Results

Electronic database searches identified 1170 articles (251 PubMed, 89 CINHAL, 358 Scopus, 270 Web of Science, 147 Cochrane Library, and 55 APA PsycInfo). After removal of 568 duplicate records, 602 articles were screened based on title and abstract. Of these, 462 studies were judged not to be relevant for various reasons, and the remaining 140 studies were sought for retrieval. Four articles were excluded because the full text was not accessible, and the remaining 136 full texts were assessed for eligibility. Among these, 129 studies were subsequently excluded as they did not meet the selection criteria for our search and another because it was an unfinished study. So, the literature selection process finally included 6 articles that were pertinent to the research topic (Fig. 1).

General characteristics of included studies

Most of the study designs were cross-sectional studies (n=4); 1 study was an RCT and 1 was a qualitative study. The characteristics of the included studies are shown in Table 2. Based on the reviewed studies, our analysis involved a sample of 1115 patients. The risk of bias, assessed using the framework proposed by JBI, found that the included studies were of good quality (range 50-100%), with a mean score of 64.41%. In particular, 1 study showed a quality of 100%, 2 studies of 62.5%, 1 study of 61.5% and 2 studies of 50%. The quality of the included studies was moderate to high; none of the selected studies were of low quality. The studies adhered to the Oxford Centre for Evidence-Based Medicine (OCEBM) [24] standards, ensuring a thorough assessment and high validity of their findings. The grade of evidence, which ranged from 1 to 3, varied based on study design (Supplementary Table 6). The full risk of bias and quality assessment algorithms are available for consultation in online Supplementary Tables 3-5.

Self-care behaviors in IBD patients

Patients with IBD encounter various psychological challenges that significantly impact their overall well-being. Effective disease management requires not only medical treatment but also psychological support to address symptoms of depression, stress and anxiety. The included studies have explored the influence of these psychological factors on the quality of life and self-care strategies in individuals with IBD.

Depression and self-care in IBD patients

Depression is a common condition among patients with IBD, and its management is crucial for improving overall well-being. Several studies have identified a correlation between depressive symptoms and reduced quality of life. For instance, Viganò *et al* [26] observed that patients with CD in remission exhibited significant levels of anxiety and depression, which

Table 1 Data extraction

Author, year [ref.]	Country	Type of study	Sample size	Objectives	Tools	Depression	Anxiety	Stress	Influence of psychosocial factors on self care	Key finding
Kennedy A, <i>et al</i> (2003) [29]	UK	RCT	IBD patients (n=240)	Evaluate the impact of a patient-centered, evidence-based guidebook on knowledge, anxiety and quality of life in patients with ulcerative colitis	Questionnaire (HADS) Guidebook	X	X		Psychological factors affect the ability to self-manage ulcerative colitis	Guidebook significantly increased patients' knowledge
Larsson K, <i>et al</i> (2017)[31]	Sweden	Qualitative study	IBD patients (n=15)	To examine disease-related stress, coping strategies and the need for information and support in patients with inflammatory bowel disease.	Interviews		X		A patient-centered guide improves knowledge and reduces anxiety	No changes were observed in anxiety levels or quality of life
Reigada LC, <i>et al</i> (2011)[30]	USA	Cross-sectional study	IBD adolescents patients (n=36)	To examine the relationship between anxiety and depression and health-related behaviors	Questionnaire (CES D) SCARED)	X	X		Better-informed patients are more capable of managing their condition	Patient-centered information is essential for involvement in chronic disease management
Edman IS, <i>et al</i> (2017)[28]	UK	Cross-sectional study	IBD patients (n=82)	To assess relationships between perceived	Questionnaire (CES D) (PSS)		X	X	Reduce stress, reduce or control symptoms related to IBD	Guidelinebook significantly increased patients' knowledge
									The patient with IBD needs various forms of support, both group and individual, which should be developed by multi-professional teams	
									Using adaptive coping strategies can improve self-care practices	
									Psychological factors (stress and coping strategies) influence self-care by influencing the daily life of (IBD) patients. High stress and social stigma can hinder effective self-management	
									Using adaptive coping strategies can improve self-care practices	
									Too much anxiety makes it difficult for adolescents to manage their condition well, leading to poorer self-management practices.	
									Addressing anxiety can improve disease management and reduce unnecessary doctor visits	
									Psychological factors (anxiety and depression) have a negative impact on IBD self-care by increasing the use of medical services.	
									Too much anxiety makes it difficult for adolescents to manage their condition well, leading to poorer self-management practices.	
									Addressing anxiety can improve disease management and reduce unnecessary doctor visits	
									Psychological factors (perceived stress) have a negative impact on	
									Stress reduction should be part of the management of GI	

(Contd...)

Table 1 (Continued)

Author, year [ref.]	Country	Type of study	Sample size	Objectives	Tools	Depression	Anxiety	Stress	Influence of psychosocial factors on self care	Key finding
Eindor-Abarbanel A, <i>et al</i> (2020) [27]	Israel	Cross-sectional study	IBD patients (n=299)	To investigate the association of illness perceptions (IPs), self-efficacy (SE) and sense of coherence (SOC) on anxiety and depression among IBD patients	Questionnaire (HADS)	X	X		self-care leading to lower quality of life and higher pain levels in IBD patients. Too much stress worsens symptom management. Reducing stress may improve self-management, improve quality of life and alleviate symptoms	patients' symptoms and illnesses. Future research should explore holistic approaches that address multiple patient symptoms
Viganò C, <i>et al</i> (2016) [26]	Italy	Cross-sectional study	IBD patients (n=123)	To assess the prevalence of depressive and anxious comorbidity in CD patients in clinical remission. To define coping strategies in those with clinical symptoms and the predictive risk factors for developing symptomatology	Questionnaire (HADS) (STAI) (PSS)	X	X	X	Psychological factors (anxiety, depression, and dysfunctional coping strategies) can compromise self-care. Lower self-efficacy and maladaptive coping hinder self-management practices, leading to poorer health outcomes and reduced quality of life. Planned psychological interventions and personalized interventions can improve disease management	Early evaluation of IP, SOC and SE among patients with IBD, and adequate interventions might prevent the development of anxiety and depression

HADS, Hospital Anxiety and Depression Scale; CES-D, Center for Epidemiologic Studies Depression scale; SCARED, Screen for Child Anxiety-Related Emotional Disorders; PSS, Perceived Stress Scale; STAI, State Trait Anxiety Inventory; CD, Crohn's disease; IBD, inflammatory bowel disease; GI, gastrointestinal

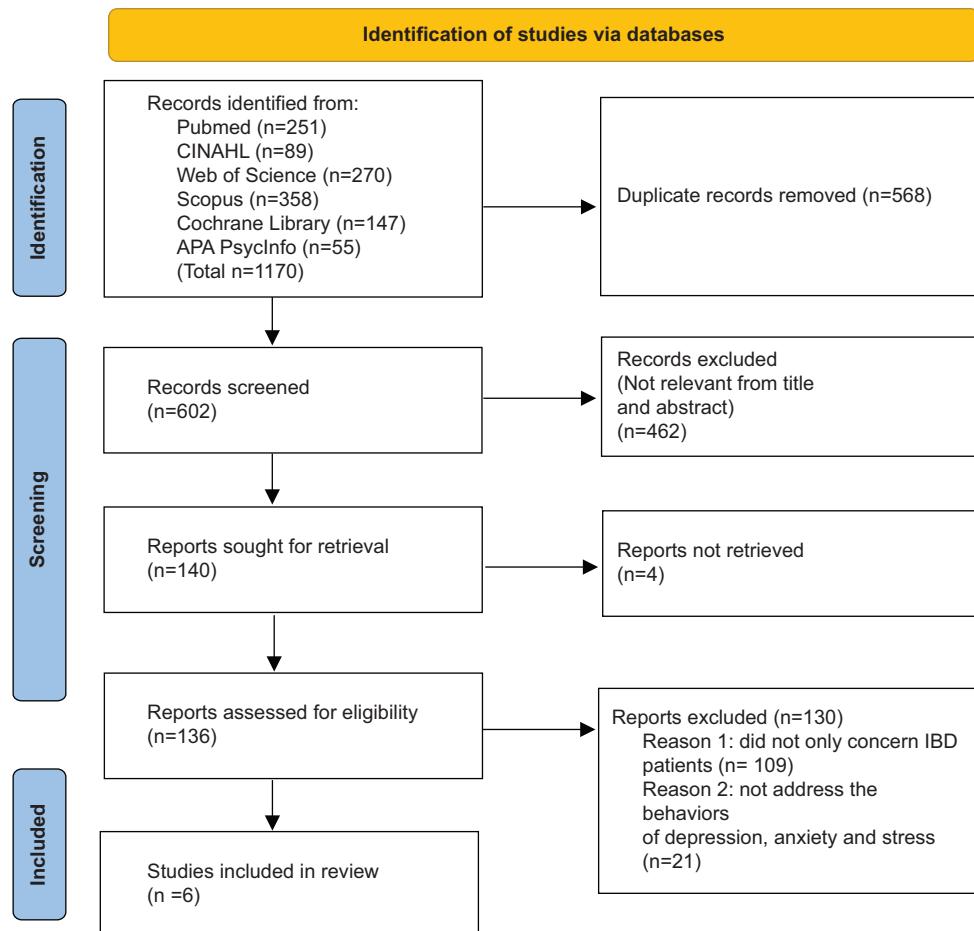


Figure 1 PRISMA flowchart reporting the process of article selection

negatively impacted their coping strategies. Notably, the adoption of dysfunctional coping mechanisms was a predictor of depression. Furthermore, patients experiencing depressive symptoms tended to seek less information about their disease and demonstrated suboptimal self-management.

Eindor-Abarbanel *et al* [27] explored the relationship between depression, self-efficacy, and disease perception, revealing that feelings of helplessness in managing the condition were strongly associated with depression. Patients with lower perceived self-efficacy in symptom management exhibited a higher prevalence of depressive and anxiety symptoms. These findings suggest that enhancing self-efficacy through educational and psychological interventions could significantly reduce depression and improve self-care.

Similarly, Edman *et al* [28] reported a strong association between perceived stress and depression in IBD patients. Elevated stress levels appeared to exacerbate mood disturbances and reduce quality of life, contributing to more severe depressive symptoms. These results underscore the importance of integrating stress management strategies into treatment plans to enhance psychological well-being.

Kennedy *et al* [29] examined the impact of an informational guide on patients with UC, assessing its effects on knowledge, anxiety, and quality of life. Their findings indicated that

providing structured information did not increase anxiety or significantly affect depression, suggesting that adequate patient education can facilitate disease self-management without adversely impacting psychological health.

Finally, Reigada *et al* [30] investigated anxiety and depression in adolescents with IBD, highlighting a high prevalence of psychological symptoms. Specifically, disease-related anxiety was associated with a greater number of medical visits and impaired social functioning. These findings emphasize the need to monitor and address anxiety symptoms in younger patients to improve disease management and overall quality of life.

Anxiety and self-care in IBD patients

Anxiety is a prevalent condition among patients with IBD, significantly impacting disease management. Kennedy *et al* [29] evaluated the effectiveness of a patient-centered manual in alleviating anxiety and improving the quality of life of individuals with UC. Their findings suggest that providing patients with comprehensive information about their condition and its management can significantly reduce anxiety and enhance self-management skills, fostering more effective self-care behaviors.

Table 2 Characteristics of included studies

Characteristic	Frequency (n=6)	Percentage
Publication year		
2020	1	16.66%
2017	2	33.33%
2016	1	16.66%
2011	1	16.66%
2003	1	16.66%
Geographical distribution		
Western Countries	5	83.30%
USA	2	33.33%
Italy	1	16.66%
Sweden	1	16.66%
United Kingdom	1	16.66%
Eastern countries	1	16.66%
Israel	1	16.66%
Type of studies		
Primary	6	100%
Cross-sectional study	4	66.6%
Qualitative study	1	16.66%
Randomized controlled study	1	16.66%

Reigada *et al* [30] investigated disease-specific anxiety in adolescents with IBD, revealing that heightened anxiety negatively affected treatment adherence and healthcare utilization. Anxious adolescents were less engaged in symptom monitoring and proactive disease management. These findings highlight the importance of early interventions aimed at reducing anxiety to improve treatment compliance and self-care practices in younger patients.

Eindor-Abarbanel *et al* [27] assessed anxiety levels in IBD patients using the Hospital Anxiety and Depression Scale (HADS), reporting a high prevalence. Anxiety was strongly associated with low self-efficacy, a diminished sense of coherence, and negative disease perceptions. The authors suggest that early identification of these psychological factors may help prevent the onset of anxiety.

Similarly, Viganò *et al* [26] examined anxiety in patients with CD in clinical remission using the HADS, identifying a prevalence rate of 36.6%. Anxiety was linked to dysfunctional coping strategies, such as limited use of positive reframing, distraction and denial. Based on these findings, the authors recommend monitoring at-risk patients to prevent the development of psychological symptoms.

Stress and self-care in IBD patients

Stress is another crucial psychological factor that can significantly impact the quality of life and self-care behaviors of patients with IBD. Larsson *et al* [31] investigated the effects of stress on disease management in patients with UC and CD, finding that psychological stress was associated with poorer disease management. Patients experiencing high levels of stress encountered greater difficulties in adopting proactive

self-care behaviors, such as dietary management and treatment adherence.

Similarly, Edman *et al* [28] examined the relationship between stress and quality of life in individuals with common gastrointestinal disorders, including IBD. Their findings revealed a strong association between perceived stress, reduced quality of life, and suboptimal disease management. These results underscore the importance of stress management as a key strategy to enhance self-care, highlighting the need to incorporate psychoeducational interventions and stress management techniques into therapeutic approaches for IBD patients.

Viganò *et al* [26] assessed stress levels in patients with CD in clinical remission using the Perceived Stress Scale, identifying elevated stress levels, particularly among those with anxiety. Stress was linked to dysfunctional coping strategies and appeared to contribute to the development of psychological symptoms. Based on these findings, the authors recommend close monitoring to identify at-risk patients and implement timely interventions.

Practical implications

IBD patients often experience depression, anxiety and stress, which negatively impact disease self-management. Depression is associated with dysfunctional coping strategies and less information-seeking about the condition, leading to poorer self-care. Anxiety affects treatment adherence and active symptom management, especially in younger patients, highlighting the need for early interventions. Lastly, stress worsens the quality of life and hinders proactive self-care behaviors, emphasizing the importance of stress management strategies to improve self-care in IBD patients. Details are shown in Table 3.

Synthesis without meta-analysis (SWiM)

In accordance with the SWiM guidelines [32], a narrative synthesis approach was adopted to integrate findings from the included studies. The synthesis was structured around key psychological constructs—depression, anxiety and stress—and their associations with self-care behaviors in patients with IBD.

Studies were grouped according to the psychological domain examined and the population characteristics (e.g., adult vs. adolescent, type of IBD). The synthesis was conducted by identifying common patterns, divergences, and the direction of effects reported across studies. To ensure consistency and transparency, data were extracted into a tabular format (Table 4) including key study characteristics, sample size, psychological constructs examined, outcomes related to self-care, and main findings.

No statistical pooling of results was performed in view of the heterogeneity of study designs, outcomes and measures used. The synthesis focused on exploring the relationship between psychological symptoms and self-care behaviors, highlighting

recurrent associations and potential mediating factors such as self-efficacy, disease perception and coping strategies.

Overall, the narrative synthesis revealed consistent trends suggesting that psychological distress negatively impacts self-care in IBD patients.

This qualitative integration provides an important foundation for developing psychosocial interventions aimed at improving disease management and health outcomes in this population.

Discussion

This systematic review highlights the critical yet underexplored role of psychological factors, namely depression, anxiety and stress, in shaping self-care practices among patients with IBD. Despite the well-documented impact of these conditions on overall health outcomes [33], their specific influence on self-care behaviors in IBD remains poorly understood. Notably, only 6 studies directly addressed this topic, underscoring a significant gap in the literature. The limited number of studies reveals the scarcity

of research dedicated to understanding how mental health interacts with self-management strategies in IBD patients. This is surprising, given the strong bidirectional relationship between psychological well-being and disease activity in chronic illnesses like IBD [34]. Anxiety, depression and stress are likely to impair patients' ability to adhere to treatment regimens [35], maintain dietary modifications [36-38], and engage in self-care behaviors critical for disease management [39,40] (Fig. 2).

Depression is a common illness that severely limits psychosocial functioning and diminishes quality of life [41]. Analyzing the main features of depression reveals its profound impact on self-care, particularly in patients with IBD. Depression encompasses a range of emotional [42], behavioral [43], cognitive [44], and physical [45] features that profoundly affect an individual's daily life. Emotional symptoms include persistent sadness [46], hopelessness [47], feelings of helplessness [48], and heightened irritability [49], which can undermine motivation [50] and engagement in self-care. Behavioral symptoms often manifest as social withdrawal [51], diminished interest in activities [52] and neglect of responsibilities [53], further disrupting routines essential for maintaining health. Cognitive symptoms such as

Table 3 Practical implications

Category	Implications for clinicians	Implications for patients
Depression & self-care	Screen for depressive symptoms in IBD patients and offer psychological interventions (e.g., CBT, mindfulness)	Engage in structured self-care routines, seek psychological support if experiencing depressive symptoms
Anxiety & self-care	Provide patient education and reassurance to reduce disease-related anxiety; consider referral for psychotherapy	Use relaxation techniques, maintain open communication with healthcare providers, and adhere to treatment plans
Stress & self-care	Incorporate stress management strategies (e.g., relaxation techniques, psychoeducation) into treatment plans	Practice stress reduction strategies (e.g., mindfulness, exercise), and participate in support groups

IBD, inflammatory bowel disease; CBT, Cognitive behavioral therapy

Table 4 Thematic synthesis of findings related to psychological factors and self-care in patients with inflammatory bowel disease

Theme	Supporting studies	Key findings
Depression and self-care	Viganò <i>et al</i> (2016) [26]; Eindor-Abarbanel <i>et al</i> (2020) [27]; Edman <i>et al</i> (2017) [28]; Kennedy <i>et al</i> (2003) [29]; Reigada <i>et al</i> (2011) [30]	Depression is associated with impaired coping, reduced self-efficacy, limited disease knowledge, and poor self-management
Anxiety and self-care	Kennedy <i>et al</i> (2003) [29]; Reigada <i>et al</i> (2011) [30]; Eindor-Abarbanel <i>et al</i> (2020) [27]; Viganò <i>et al</i> (2016) [26]	Anxiety correlates with low self-efficacy, dysfunctional coping, reduced treatment adherence, and negative illness perception
Stress and self-care	Larsson <i>et al</i> (2017) [31]; Edman <i>et al</i> (2017) [28]; Viganò <i>et al</i> (2016) [26]	High perceived stress lowers quality of life and hinders effective self-care behaviors
Role of self-efficacy	Eindor-Abarbanel <i>et al</i> (2020) [27]; Kennedy <i>et al</i> (2003) [29]	Self-efficacy mediates the impact of psychological symptoms on disease management. Educational support may improve self-care
Dysfunctional coping strategies	Viganò <i>et al</i> (2016) [26]; Edman <i>et al</i> (2017) [28]	Maladaptive coping (e.g., denial, avoidance) worsens psychological symptoms and self-management capacity
Psychological burden in adolescents	Reigada <i>et al</i> (2011) [30]	Adolescents with IBD experience significant anxiety and depression, affecting social interaction and treatment adherence

The table summarizes thematic areas and evidence derived from included studies. It provides a narrative synthesis in line with SWiM recommendations for systematic reviews without meta-analysis

IBD, inflammatory bowel disease

negative thought patterns [54], impaired concentration [55], indecisiveness [56], and feelings of worthlessness [57] create additional challenges in problem-solving and decision-making related to disease management. Finally, physical symptoms like fatigue [58], sleep disturbances [59], appetite changes [60], and somatic complaints [61] add to the overall burden of the illness, compounding the difficulties of adhering to self-care practices. On a more philosophical level, a depressed individual may perceive life as devoid of meaning and purpose [62]. His perspective can lead to a state of resignation, where the individual passively endures life and illness rather than actively engaging in self-care behaviors. This mindset can perpetuate a cycle of neglect, undermining the proactive management of their health and well-being. Consequently, interventions to instill a renewed sense of purpose in life [63] could play a crucial role. Encouraging acceptance of the illness contrary to denial or, in some cases, indifference might yield positive outcomes in terms of self-care behaviors [64], improved health outcomes and enhanced quality of life [65]. Acceptance enables individuals to approach their condition with greater awareness and adaptability, fostering proactive engagement in managing their health and well-being. Furthermore, it is well-established that psychological interventions can increase levels of self-acceptance [66], which may further support the development of effective self-care practices and overall resilience.

When a new diagnosis is made particularly one that entails long-term, chronic treatment prospects, or more precisely *ad vitam*, it can provoke a state of anxiety [67,68]. In such cases, anxiety can play 2 diametrically opposed roles. On the one hand, anxiety may trigger fear (and *vice versa*) [69], and catastrophic [70] negative thoughts [71] about one's condition, leading to an emotional distancing from the identity of being a patient. This can result in avoidance behaviors [72] that steer the individual away from essential self-care practices. The

avoidance mechanism can become so overwhelming that the patient passively succumbs to their condition, feeling trapped in doubt [73] and indecision [74] regarding a disease they perceive as uncontrollable, further exacerbated by their mental state.

On the other hand, anxiety may drive hyper-controlling behaviors [75] related to the illness, which could paradoxically seem beneficial at first. Such patients might frequently seek explanations from their physician, request additional tests to understand the status of their disease better, or inquire about experimental therapies. However, this can result in overdiagnosis/overtreatment, which may ultimately be harmful to the patient [76]. While this hypervigilance may initially appear as proactive, it often masks the danger of a life overly centered on their illness. In severe cases, this can lead to obsessive-compulsive cycles [77], dominating their life to the point where it becomes unlivable as they are entirely "subjugated" to the disease. It is therefore essential to strike a balance, avoiding both extremes.

Targeted interventions to manage anxiety can significantly mitigate its dysfunctional effects, including poor disease management and impaired self-care behaviors. By addressing anxiety, patients may achieve a more adaptive approach to their condition, fostering better health outcomes and quality of life. When discussing stress in its broadest sense, we can assert that it is an integral component of both anxiety disorders and depressive disorders [78]. Stress, defined as the body's response to any demand or challenge that disrupts its equilibrium [79], significantly influences disease outcomes [79]. IBD patients face a substantial burden of stress, which significantly impacts their quality of life and disease outcomes. Stress is a well-documented trigger for acute flares in both pediatric and adult IBD patients, further exacerbating disease severity [80]. Stress is an integral part of the disease for many reasons, primarily related to the long-term follow up required, and the necessity

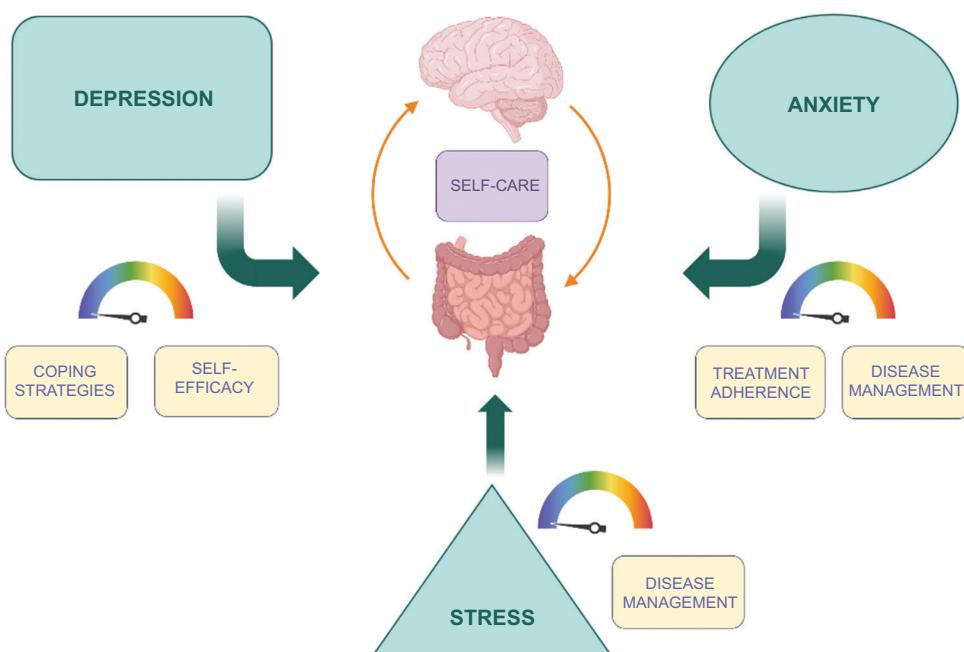


Figure 2 The figure shows psychological factors in shaping self-care

of frequent medical visits—as evidenced by the increased number of emergency room visits for IBD-related conditions over time [81,82]. Additionally, patients face challenges in adapting to social settings, such as dining out, being at work, and participating in social and cultural activities, because of their symptoms [81]. Several studies have shown, across various chronic illnesses and in both patients and caregivers, that stress can negatively impact self-care behavior and health behavior in general [8]. According to theoretical models, stress can overwhelm coping resources [83-85], leading to maladaptive responses. Additionally, chronic stress significantly impacts cognitive [86] and emotional functioning [87], leading to impaired decision-making [88] and decreased adherence to disease management strategies. This was highlighted in a recent cross-sectional study of IBD patients, which identified poor stress coping as a significant predictor of non-compliance, among other factors [89]. Recognizing the detrimental effects of stress, the European Crohn's and Colitis Organisation's guidelines recommend screening IBD patients for psychological distress and offering psychotherapy or psychopharmacological treatment when necessary [90]. Targeting stress has proven to enhance disease outcomes [91], underscoring the importance of integrated care in managing IBD [92].

Considering the bigger picture, where depression, anxiety, stress, and their impact on self-care coexist, it becomes evident that further research and perhaps even more curiosity is needed to study self-care as a central element in the management and treatment of chronic conditions like IBD. As previously mentioned, our rigorous research identified only 6 articles addressing how depression, anxiety and stress influence self-care in IBD. With this review, we aim to make an appeal to all healthcare professionals working closely with patients affected by IBD. A close collaboration among gastroenterologists, psychiatrists, psychologists and nurses is essential. On the one hand, such collaboration fosters mutual enrichment and knowledge exchange, and on the other, it ensures that the treatment of IBD becomes truly integrated, leaving no aspect unaddressed that could potentially benefit the patient.

The small number of included studies (n=6) and the predominance of cross-sectional designs limit the ability to draw causal conclusions. The variability in methodologies and outcome measures may also hinder direct comparisons across studies. The lack of interventional studies further limits our capacity to assess the effectiveness of psychological interventions. Another limitation is that not all available biomedical databases were consulted, which may have resulted in missing relevant studies. Future research should prioritize longitudinal and interventional studies with larger sample sizes to better understand causal relationships and identify effective psychological interventions. The use of standardized assessment tools and more inclusive sample populations would enhance the comparability of results and improve their clinical applicability.

In conclusion, the findings of this study underscore the critical importance of addressing psychological factors in patients with IBD, specifically depression, anxiety and stress, all of which negatively impact self-care strategies and quality of life. Implementing educational and psychological interventions

designed to enhance self-efficacy, reduce anxiety and manage stress could facilitate more effective self-care behaviors. Early psychological involvement is likely to improve treatment adherence and disease management. Integrating psychological support into therapeutic pathways is a crucial strategy to optimize IBD management and enhance patients' overall well-being.

Acknowledgment

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Supplementary material

Supplementary Table 1 PRISMA checklist

Section and Topic	Item#	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review	1
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist	1
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge	3
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses	4
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses	5
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted	5
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used	4
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process	5-6
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process	6
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g., for all measures, time points, analyses), and if not, the methods used to decide which results to collect	6
	10b	List and define all other variables for which data were sought (e.g., participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information	6
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process	5-6
Effect measures	12	Specify for each outcome the effect measure(s) (e.g., risk ratio, mean difference) used in the synthesis or presentation of results	6
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g., tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5))	6
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions	6
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses	6
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used	6
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g., subgroup analysis, meta-regression)	6
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results	7

(Contd...)

Supplementary Table 1 (Continued)

Section and Topic	Item#	Checklist item	Location where item is reported
METHODS			
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases)	5-6
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome	6
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram	8
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded	8-11
Study characteristics	17	Cite each included study and present its characteristics	8
Risk of bias in studies	18	Present assessments of risk of bias for each included study	8
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g., confidence/credible interval), ideally using structured tables or plots	8
Results of syntheses	20a	For each synthesis, briefly summarize the characteristics and risk of bias among contributing studies	Supplementary material 1
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g., confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect	Supplementary material 1
	20c	Present results of all investigations of possible causes of heterogeneity among study results	Supplementary material 1
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results	Supplementary material 1
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed	8
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed	8
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence	12
	23b	Discuss any limitations of the evidence included in the review	12-15
	23c	Discuss any limitations of the review processes used	15-16
	23d	Discuss implications of the results for practice, policy, and future research	15-16
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered	4
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared	4
	24c	Describe and explain any amendments to information provided at registration or in the protocol	4
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review	16
Competing interests	26	Declare any competing interests of review authors	16
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review	16

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, *et al.* The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. doi: 10.1136/bmj.n71. This work is licensed under CC BY 4.0. To view a copy of this license, visit <https://creativecommons.org/licenses/by/4.0/>

Supplementary Table 2 Search strategy

Pubmed: n=251

#1	((inflammatory bowel diseases) OR (crohn disease)) OR (ulcerative colitis)
#2	(((self-care) OR (self-car*)) OR (self-monitoring)) OR (self management) OR (self efficacy)))
#3	(((Anxiety) OR (stress)) OR (depression))
#4	(((inflammatory bowel diseases) OR (crohn disease)) OR (ulcerative colitis)) AND (((self-care) OR (self-car*)) OR (self-monitoring)) OR (self management) OR (self efficacy))) AND (((Anxiety) OR (stress)) OR (depression))
#5	#1 AND #2 AND #3

CINHAL: n= 89

#1	(((inflammatory bowel diseases) OR (crohn disease)) OR (ulcerative colitis))
#2	(((self-care) OR (self-car*)) OR (self-monitoring)) OR (self management) OR (self efficacy)))
#3	(((Anxiety) OR (stress)) OR (depression))
#4	(((inflammatory bowel diseases) OR (crohn disease)) OR (ulcerative colitis)) AND (((self-care) OR (self-car*)) OR (self-monitoring)) OR (self management) OR (self efficacy))) AND (((Anxiety) OR (stress)) OR (depression))
#5	#1 AND #2 AND #3

Web of Science: n=270

#1	(((inflammatory bowel diseases) OR (crohn disease)) OR (ulcerative colitis))
#2	(((self-care) OR (self-car*)) OR (self-monitoring)) OR (self management) OR (self efficacy)))
#3	(((Anxiety) OR (stress)) OR (depression))
#4	(((inflammatory bowel diseases) OR (crohn disease)) OR (ulcerative colitis)) AND (((self-care) OR (self-car*)) OR (self-monitoring)) OR (self management) OR (self efficacy))) AND (((Anxiety) OR (stress)) OR (depression)) (All Fields)
#5	#1 AND #2 AND #3

Scopus: n=358

#1	TITLE-ABS-KEY (((((inflammatory AND bowel AND diseases) OR (crohn AND disease)) OR (ulcerative AND colitis)))
#2	TITLE-ABS-KEY (((((self-care) OR (self-car*)) OR (self-monitoring)) OR (self AND management)) OR (self AND efficacy)))
#3	TITLE-ABS-KEY (((anxiety) OR (stress)) OR (depression)))
#4	TITLE-ABS-KEY (((((inflammatory AND bowel AND diseases) OR (crohn AND disease)) OR (ulcerative AND colitis)) AND (((self-care) OR (self-car*)) OR (self-monitoring)) OR (self AND management)) OR (self AND efficacy))) AND (((anxiety) OR (stress)) OR (depression)))
#5	#1 AND #2 AND #3

APA PsycInfo: n=55

#1	((((inflammatory bowel diseases) OR (crohn disease)) OR (ulcerative colitis)))
#2	((((self-care) OR (self-car*)) OR (self-monitoring)) OR (self management) OR (self efficacy)))
#3	(((Anxiety) OR (stress)) OR (depression))
#4	((((inflammatory bowel diseases) OR (crohn disease)) OR (ulcerative colitis)) AND (((self-care) OR (self-car*)) OR (self-monitoring)) OR (self management) OR (self efficacy))) AND (((Anxiety) OR (stress)) OR (depression)))
#5	#1 AND #2 AND #3

Cochrane Library: n=147

#1	(inflammatory bowel diseases) OR (crohn disease) OR (ulcerative colitis)
#2	(self-care) OR (self-car*) OR (self-monitoring) OR (self management) OR (self efficacy)
#3	(Anxiety) OR (stress) OR (depression)
#4	(inflammatory bowel diseases) OR (crohn disease) OR (ulcerative colitis) in All Text AND (self-care) OR (self-car*) OR (self-monitoring) OR (self management) OR (self efficacy) in All Text AND (Anxiety) OR (stress) OR (depression) in All Text - (Word variations have been searched)
#5	#1 AND #2 AND #3

Total articles found: 1170

Supplementary Table 3 Critical appraisal tool for randomized controlled trials

Study [ref.]	JBI Critical appraisal of randomized control studies													Score mean (%)	Level	
	Item 1	Item 2	Item 3	Item 4	Item 5	Item 6	Item 7	Item 8	Item 9	Item 10	Item 11	Item 12	Item 13			
Kennedy <i>et al.</i> , 2003 [29]	Y	Y	Y	U	N	N	Y	Y	Y	Y	NA	U	Y	YES	61.5	Moderate

Items from JBI Critical appraisal tool for randomized controlled trials: 1. Was true randomization used for assignment of participants to treatment groups? 2. Was allocation to treatment groups concealed? 3. Were treatment groups similar at the baseline? 4. Were participants blind to treatment assignment? 5. Were those delivering treatment blind to treatment assignment? 6. Were outcomes assessors blind to treatment assignment? 7. Were treatment groups treated identically other than the intervention of interest? 8. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analyzed? 9. Were participants analyzed in the groups to which they were randomized? 10. Were outcomes measured in the same way for treatment groups? 11. Were outcomes measured in a reliable way? 12. Was appropriate statistical analysis used? 13. Was the trial design appropriate, and any deviations from the standard RCT design (individual randomization, parallel groups) accounted for in the conduct and analysis of the trial?

JBI, Joanna Briggs Institute; Y, yes; N, no; U, unclear; NA, not applicable

Level: percentage above 70 high level, percentage between 50 and 69 moderate level, percentage below 49 low level RCT, randomized controlled trial

Supplementary Table 4 Critical appraisal tool for analytical cross-sectional studies

Study [ref.]	JBI Critical appraisal of analytical cross-sectional studies										Score mean (%)	Level
	Item 1	Item 2	Item 3	Item 4	Item 5	Item 6	Item 7	Item 8	Include			
Viganò <i>et al.</i> , 2016 [26]	Y	Y	U	Y	N	U	Y	Y	YES	62.5	Moderate	
Eindor-Abarbanel <i>et al.</i> , 2020 [27]	Y	Y	N	Y	N	NA	N	Y	YES	50	Moderate	
Reigada <i>et al.</i> , 2011 [30]	N	Y	NA	Y	Y	Y	N	Y	YES	62.5	Moderate	
Edman <i>et al.</i> , 2017 [28]	Y	Y	NA	Y	N	NA	N	Y	YES	50	Moderate	

Items from JBI Critical appraisal tool for analytical cross-sectional studies: 1. Were the criteria for inclusion in the sample clearly defined? 2. Were the study subjects and the setting described in detail? 3) Was the exposure measured in a valid and reliable way? 4) Were objective, standard criteria used for measurement of the condition? 5) Were confounding factors identified? 6) Were strategies to deal with confounding factors stated? 7) Were the outcomes measured in a valid and reliable way? 8) Was appropriate statistical analysis used?

JBI, Joanna Briggs Institute; Y, yes; N, no; U, unclear; NA, not applicable

Level: percentage above 70 high level, percentage between 50 and 69 moderate level, percentage below 49 low level

Supplementary Table 5 Critical appraisal tool for qualitative studies

Study [ref.]	JBI Critical appraisal of qualitative research										Score mean (%)	Level	
	Item 1	Item 2	Item 3	Item 4	Item 5	Item 6	Item 7	Item 8	Item 9	Item 10			
Larsson <i>et al.</i> , 2017 [3]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	YES	100%	High

Items from JBI Critical appraisal tool for analytical cross-sectional studies: 1. Is there congruity between the stated philosophical perspective and the research methodology? 2. Is there congruity between the research methodology and the research question or objectives? 3) Is there congruity between the research methodology and the methods used to collect data? 4) Is there congruity between the research methodology and the representation and analysis of data? 5) Is there congruity between the research methodology and the interpretation of result? 6) Is there a statement locating the researcher culturally or theoretically? 7) Is the influence of the researcher on the research, and vice-versa, addressed? 8) Are participants, and their voices, adequately represented? 9) Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body? 10) Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?

JBI, Joanna Briggs Institute; Y, yes; N, no; U, unclear; NA, not applicable

Level: percentage above 70 high level, percentage between 50 and 69 moderate level, percentage below 49 low level

Supplementary Table 6 Oxford Centre for Evidence-Based Medicine (OCEBM) level of evidence

Studies included [ref.]	Study design	OCEBM*
Kennedy <i>et al.</i> , 2003 [29]	RCT	1
Larsson <i>et al.</i> , 2017 [31]	Qualitative study	2
Reigada <i>et al.</i> , 2011 [30]	Cross sectional study	2
Edman <i>et al.</i> , 2017 [28]	Cross sectional study	2
Eindor-Abarban <i>et al.</i> , 2020 [27]	Cross sectional study	2
Viganò <i>et al.</i> , 2016 [26]	Cross sectional study	2

*RCT, Randomized Controlled Trial; *Range 1 (minimum) - 3 (maximum)*