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Self-Care Behaviors and Quality of Life in Inflammatory Bowel Disease Patients: A Multicentre Study

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Abstract

Introduction. Health-related quality of life (HRQoL) is substantially impaired in individuals living with inflammatory bowel disease (IBD). Although self-care is considered a key component of chronic disease management, the specific contributions of different self-care dimensions to physical and mental HRQoL remain poorly understood. This study examined the relationship between self-care behaviours and HRQoL in patients with IBD.

Methods. A multicentre cross-sectional study was conducted among 453 adult patients with Crohn's disease or ulcerative colitis recruited from outpatient IBD centres in Italy. Self-care

was assessed using the Self-Care of Chronic Illness Inventory (SC-CII), and HRQoL was measured using the 12-Item Short Form Health Survey (SF-12). Generalized Additive Models (GAMs) adjusted through Directed Acyclic Graph (DAG)-informed confounding control were used to investigate linear and nonlinear associations between self-care dimensions and HRQoL.

Results. Self-care monitoring showed the highest mean score, whereas self-care maintenance and management were below the established adequacy threshold. No significant associations emerged between self-care dimensions and mental HRQoL. A weak nonlinear association was observed between self-care management and physical HRQoL, suggesting that higher management behaviours may reflect increased disease burden rather than better health status. Overall model fit was limited (adjusted $R^2 = 0.024$ for PCS-12 and −0.002 for MCS-12), indicating that self-care explained only a small proportion of HRQoL variability.

Discussion. The findings suggest that self-care behaviours alone may not fully explain variations in HRQoL among patients with IBD. Physical and mental well-being appear to be influenced by a complex interplay of clinical, psychological, and behavioural factors. Future longitudinal studies should explore the role of psychosocial determinants and causal pathways linking self-care and quality of life.

Keyword: Inflammatory Bowel Disease, Self-Care, Quality of Life, Nursing, Chronic Disease, Patient-Reported Outcome

Introduction

Inflammatory bowel disease (IBD), encompassing Crohn's disease (CD) and ulcerative colitis (UC), is a chronic relapsing-remitting condition with a substantial and growing global burden. The prevalence of IBD exceeds 0.3% in North America, Oceania, and many European countries, with the highest reported values reaching 505 per 100,000 for UC in Norway and 322 per 100,000 for CD in Germany (Ng et al., 2017). In 2019, approximately 4.9 million cases were estimated worldwide, with incidence rising rapidly in newly industrialized regions (Wang et al., 2025). The prevalence in the Western world is projected to reach 1% by 2030, potentially affecting 10 million individuals (Kaplan & Windsor, 2021).

IBD significantly impairs health-related quality of life (HRQoL) across physical, psychological, and social domains (Casellas et al., 2001; Knowles et al., 2018). This impairment is most pronounced during active disease, whereas clinical remission is associated with HRQoL levels approaching general-population norms. Psychological factors, particularly depression and anxiety, are among the strongest determinants of poor HRQoL, often exerting effects independent of, and sometimes exceeding, those of physical symptoms (Thomann et al., 2023; Zhang et al., 2013). Additional contributors include maladaptive coping, visceral sensitivity, illness identity, and food-related distress, which interact with inflammatory burden to further compromise nutritional status and social participation (Almarzouki et al., 2024; Whelan et al., 2021).

The Middle-Range Theory of Self-Care of Chronic Illness conceptualizes self-care as a dynamic process comprising three distinct but interrelated dimensions (Riegel et al., 2012): self-care maintenance, referring to

behaviours aimed at maintaining health and disease stability (e.g., adhering to prescribed medication, maintaining an appropriate diet, and engaging in regular physical activity); self-care monitoring, involving the observation and recognition of changes in signs and symptoms (e.g., monitoring stool frequency, rectal bleeding, abdominal pain, or bowel urgency); and self-care management, referring to actions taken in response to symptoms when they occur (e.g., contacting the IBD care team when symptoms worsen, seeking timely clinical assessment, or implementing previously agreed symptom-management strategies). Within this theoretical framework, these dimensions represent complementary components of the self-care process and may relate differently to clinical and patient-reported outcomes.

The relationship between self-care and health-related quality of life (HRQoL) in chronic illnesses is well established in the literature. Higher levels of self-care, particularly self-care maintenance, are consistently associated with significant improvements in both physical and mental HRQoL, whereas self-care monitoring and self-care management appear to show weaker or context-dependent associations (Cai et al., 2025; Kim et al., 2026). This relationship is mediated by factors such as self-efficacy and self-care confidence, which influence the overall self-care process and, consequently, clinical outcomes (Chin et al., 2021; Peters et al., 2019).

Self-care capacity in IBD is influenced by multiple psychological, personal, and relational factors. Higher self-efficacy, health literacy, resilience, and nurse-patient mutuality are associated with better self-care behaviours and improved disease outcomes, whereas health anxiety and greater disease severity negatively affect self-care capacity (Napolitano, Bassola, et al., 2026; Napolitano, Bozzetti, et al., 2025; Napolitano, Cilluffo, Marini, et al., 2025; Papp-Zipernovszky et al., 2026; Sheehan et al., 2024; Stone et al., 2022). Overall, current evidence supports an integrated theoretical approach to understanding self-care in IBD (Napolitano, Bozzetti, et al., 2026).

Despite growing evidence linking self-care to HRQoL, the mechanisms through which different self-care dimensions influence patient-reported outcomes remain insufficiently understood. Low levels of self-care, health literacy, and self-care agency are consistently associated with poorer HRQoL (Hu & Xu, 2024; Lovén Wickman et al., 2019; Napolitano, Biagioli, et al., 2025).

Mediation analyses indicate that self-care and health literacy independently and sequentially mediate the relationship between psychological distress and HRQoL, suggesting that self-care deficits directly contribute to worse outcomes (Hu & Xu, 2024; Tormey et al., 2019).

However, most existing studies rely on descriptive or correlational designs, and robust predictive models testing self-care as a direct determinant of HRQoL are scarce (Barello et al., 2021; Demers et al., 2025). In particular, the independent contribution of self-care maintenance, monitoring, and management to physical and mental HRQoL remains underexplored, and previous investigations have predominantly employed linear analytical approaches, potentially overlooking complex nonlinear associations.

Aim

The aim of this study is to examine the associations between the different dimensions of self-care and physical and mental HRQoL in patients with IBD.

Methods

Study design

A multicentre, observational, cross-sectional study was conducted as a secondary analysis of baseline data from the multicentre longitudinal IBD-SELF study (Napolitano et al., 2024). Reporting adhered to the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines for cross-sectional studies (von Elm et al., 2008).

Ethical Considerations

The study was conducted in accordance with Good Clinical Practice and the Revised Declaration of Helsinki. The Territorial Ethics Committee (Lazio 3) reviewed and approved the protocol (Approval No. 0023486/23, dated August 2, 2023). Before enrollment, all participants received detailed oral and written information regarding the study's objectives and procedures and provided written informed consent.

Study size

This study represents a secondary analysis of data collected within the IBD-SELF study, whose protocol and sample size determination have been previously published (Napolitano et al., 2024). The parent study planned to recruit at least 250 patients with IBD. The original sample size was based on an approximately 10:1 ratio between cases and model parameters, with 200 participants considered sufficient to achieve 80% power for a moderate effect size (0.4). For the present secondary analysis, all eligible patients with complete data available for the variables of interest were included, resulting in a final analytic sample of 453 participants.

Participants and setting

Consecutive adult patients were recruited from outpatient IBD units across northern, central, and southern Italy to enhance geographic representativeness. Eligibility criteria included: age ≥18 years, a confirmed diagnosis of CD or UC, the ability to read and understand Italian, and written informed consent. Exclusion criteria were: diagnosis within the previous 12 months, IBD-related surgery within the previous 6 months, presence of another severe symptomatic chronic disease, and cognitive impairment precluding questionnaire completion. Participants were enrolled during routine outpatient visits by trained IBD nurses.

Measures

Health-related quality of life

HRQoL was assessed using the 12-Item Short Form Health Survey (SF-12), a widely validated instrument derived from the SF-36 (Ware et al., 1996). Two summary scores were computed: the Physical Component Summary (PCS-12) and the Mental Component Summary (MCS-12). Both scores are norm-based, standardised to a mean of 50 and a standard deviation of 10 in the general US population, with higher scores indicating better perceived health (Jakobsson et al., 2012; Ware et al., 1996). The SF-12 has been previously used to assess generic HRQoL in IBD populations (Tiles-Sar et al., 2025)

Self-care

Self-care was evaluated using the Self-Care of Chronic Illness Inventory (SC-CII), a theory-based tool grounded in the Middle-Range Theory of Self-Care for Chronic Illness. The SC-CII assesses three scales: self-care maintenance, self-care monitoring, and self-care management—each rated on a standardized 0–100 scale, with higher scores indicating better self-care and a cutoff of 70 signifying adequate levels (Vellone, Lorini, et al., 2020). The instrument has demonstrated strong reliability and construct validity across diverse chronic disease populations (Ling et al., 2021; Riegel et al., 2018; Vellone, Barbaranelli, et al., 2020) and has been specifically validated in patients with IBD, confirming its factorial validity and internal consistency (Napolitano, Biagioli, et al., 2025).

Sociodemographic and clinical variables

Sociodemographic and clinical characteristics were collected to describe the study population and to adjust for potential confounding in multivariable analyses. Age and years since diagnosis were treated as continuous variables. Sex was coded as male or female. Educational level was categorised into four groups: primary school, middle school, high school, and bachelor's degree or higher. IBD type was recorded as CD or UC. Disease activity was classified as remission, mild, moderate, or severe, based on validated clinical indices routinely used in outpatient care: the Harvey-Bradshaw Index (HBI) for CD and the Mayo Score for UC (Harvey & Bradshaw, 1980; Lewis et al., 2008).

The HBI is a simplified clinical index based on five variables (general well-being, abdominal pain severity, number of liquid stools daily, abdominal mass, and complications), with scores ≤4 indicating remission. The Mayo Score assesses stool frequency, rectal bleeding, mucosal appearance at endoscopy, and the physician's global assessment, with lower scores indicating less active disease. Smoking status was recorded as non-smoker, former smoker, or current smoker. All clinical variables were retrieved from medical records at the time of the outpatient visit, ensuring temporal alignment between patient-reported and clinical data.

Statistical Analysis

Analyses were performed using R, version 4.5.0 (R Core Team, 2023). The relationship between SC-CII Maintenance, Monitoring, and Management and patients' HRQoL (SF-12 Physical Component Summary [PCS-12] and Mental Component Summary [MCS-12]) was investigated through Generalized Additive Models (GAMs) using the *mgcv* package. GAMs are a flexible extension of the Generalized Linear Model (GLM) framework that allow nonlinear relationships between predictors and outcomes to be estimated through smooth functions (smooth splines). Unlike linear models, which assume a constant rate of change across the range of the predictor, GAMs approximate complex, potentially curvilinear associations without pre-specifying their functional form. This flexibility is particularly useful in psychosocial and clinical research, where effects may not be linear—for instance, incremental increases in self-care behaviours may be associated with HRQoL only up to a saturation point, beyond which further increases may have minimal or different effects. Formally, a GAM models the expected value of the outcome Y as:

$$g\,(E[Y]) = \beta_0 + s_1(X_1) + s_2(X_2) + \ldots\ldots + \varepsilon$$

where g is a link function (identity in our case), and $s_i(X_i)$ are smooth functions estimated by penalized regression splines. The degree of smoothness is selected automatically by Restricted Maximum Likelihood (REML), balancing goodness of fit and model parsimony to prevent overfitting. Although Structural Equation Modeling (SEM) could also capture latent constructs and interrelations between variables, it requires the specification of linear relationships and a predefined causal structure. Given our interest in detecting potential nonlinear associations between specific observed measures (SC-CII subscales and SF-12 scores), GAMs provided a more robust and data-driven alternative. In contrast to SEM, GAMs do not rely on multivariate normality, are less sensitive to small-sample misspecification, and can flexibly model non-linear effects even with limited sample size, provided penalization is applied. Potential confounding was examined using Directed Acyclic Graphs (DAGs) constructed with the *dagitty* package in R (Textor et al., 2011).

DAGs are graphical representations of hypothesized causal relationships between variables, where nodes represent variables and arrows represent directed causal effects. They are acyclic, meaning that no variable can causally influence itself through a feedback loop. DAG-based causal reasoning identifies which variables need to be statistically controlled (the minimal sufficient adjustment set) to obtain an unbiased estimate of the exposure–outcome relationship. In the present study, the DAG was specified to reflect theoretical and empirical knowledge on self-care and quality of life in IBD patients. Sociodemographic characteristics (age, gender, education) and disease-related variables (pathology, disease activity, years since diagnosis, and smoking status) were assumed to influence both self-care (SC-CII scales) and HRQoL, and were therefore modelled as potential confounders. Based on this causal structure, the dagitty analysis identified a minimal sufficient adjustment set comprising age, gender, education, pathology, disease activity, years since diagnosis, and smoking status. All GAMs estimating the associations between SC-CII subscales and SF-12 (PCS-12 and MCS-12) outcomes were accordingly adjusted for this set to approximate the total association under the assumed causal model.

Results

A total of 453 patients were included in the analyses. Descriptive statistics for all study variables are presented in Table 1. The sample was balanced by sex (49.0% female, 51.0% male) and IBD type (49.2% CD, 50.8% UC). Mean age was 43.85 years (SD = 16.28), and mean disease duration was 11.64 years (SD = 9.37). The majority of participants were in clinical remission (57.2%), while 15.5% had mild, 15.5% moderate, and 11.9% severe disease activity. Regarding education, 44.6% had completed high school and 32.5% held a bachelor's degree or higher.

Mean HRQoL scores were 45.95 (SD = 5.62) for PCS-12 and 37.05 (SD = 8.66) for MCS-12, indicating physical health slightly below the general population norm (50) and substantially impaired mental health. Mean SC-CII scores were 69.75 (SD = 11.33) for maintenance, 80.59 (SD = 17.63) for monitoring, and 68.79 (SD = 16.75) for management. Using the established adequacy threshold of ≥70 (Vellone, Barbaranelli, et al., 2020), mean maintenance

and management scores fell below the cutoff, while monitoring exceeded it.

Table 1. Descriptive statistics for study variables.

Variable	Values
HRQoL, M (SD)	
PCS-12	45.95 (5.62)
MCS-12	37.05 (8.66)
SC-CII scales, M (SD)	
SC-CII Maintenance	69.75 (11.33)
SC-CII Monitoring	80.59 (17.63)
SC-CII Management	68.79 (16.75)
Age (years), M (SD)	43.85 (16.28)
Years since diagnosis, M (SD)	11.64 (9.37)
Sex, n (%)	
Female	222 (49.0%)
Male	231 (51.0%)
Education, n (%)	
Bachelor's degree or higher	147 (32.5%)
Primary school	15 (3.3%)
High school	202 (44.6%)
Middle school	89 (19.6%)
IBD type, n (%)	
Crohn's disease	223 (49.2%)
Ulcerative colitis	230 (50.8%)
Disease activity, n (%)	
Mild	70 (15.5%)
Moderate	70 (15.5%)
Remission	259 (57.2%)
Severe	54 (11.9%)
Smoking status, n (%)	
Former smoker	125 (27.6%)
Non-smoker	230 (50.8%)
Current smoker	98 (21.6%)

Note. HRQoL = health-related quality of life; PCS-12 = Physical Component Summary of the 12-Item Short Form Health Survey; MCS-12 = Mental Component Summary; SC-CII = Self-Care of Chronic Illness Inventory; IBD = inflammatory bowel disease. Values are reported as mean (standard deviation) for continuous variables and number (percentage) for categorical variables. Percentages may not sum to exactly 100% due to rounding.

Association Between Health-Related Quality of Life and SC-CII

Physical Health-related quality of life (PCS-12)

In DAG-adjusted GAMs (Table 2), SC-CII Management showed a statistically significant nonlinear association with PCS-12 (edf = 3.09; F = 2.73; p = 0.035). No evidence of association was observed for SC-CII Maintenance (edf = 1.00; p = 0.775) or Monitoring (edf = 1.00; p = 0.833). Overall model fit was weak (adjusted R^2 = 0.024; deviance explained = 6.65%).

Model-based contrasts were consistent with these findings. Moving from the 25th to the 75th percentile of SC-CII Management (60.00 to 80.00) was associated with a decrease in PCS-12 (Δ[75–25] = −1.10; 95% CI −2.24 to 0.04), suggesting a nonlinear pattern in which higher management scores were not uniformly associated with better physical HRQoL. Corresponding contrasts for Maintenance (Δ[75–25] = 0.13; 95% CI −0.78 to 1.05) and Monitoring (Δ[75–25] = 0.09; 95% CI −0.73 to 0.91) were small and non-significant.

Mental Health-Related Quality of Life (MCS-12)

In DAG-adjusted GAMs (Table 3), no SC-CII domain showed a statistically significant association with MCS-12. The smooth terms for Maintenance (edf = 1.37; F = 2.49; p = 0.136), Monitoring (edf = 1.00; F = 0.63; p = 0.428), and Management (edf = 1.00; F = 0.41; p = 0.523) were all non-significant. Overall model fit was poor (adjusted R^2 = −0.002; deviance explained = 3.66%).

Model-based contrasts confirmed these null findings. Moving from the 25th to the 75th percentile of SC-CII Maintenance was associated with a non-significant decrease in MCS-12 (Δ[75–25] = −1.29; 95% CI −2.79 to 0.22). Corresponding contrasts for Monitoring (Δ[75–25] = −0.51; 95% CI −1.78 to 0.75) and Management (Δ[75–25] = 0.34; 95% CI −0.71 to 1.39) were similarly non-significant. Models visualization is depicted in Figure 1.

Mental Health-Related Quality of Life (MCS-12)

In DAG-adjusted GAMs (Table 3), no SC-CII domain showed a statistically significant association with MCS-12. The smooth terms for

Table 2. Generalized additive models for PCS-12.

Associated Term	edf	F	*p*	25th percentile	75th percentile	Δ (75–25)	95% CI lower	95% CI upper
SC-CII Maintenance	1.00	0.08	0.775	60.70	78.60	0.13	−0.78	1.05
SC-CII Monitoring	1.00	0.04	0.833	70.00	95.00	0.09	−0.73	0.91
SC-CII Management	3.09	2.73	0.035	60.00	80.00	−1.10	−2.24	0.04

Note. edf = effective degrees of freedom for the smooth term; F = approximate F statistic for the smooth function. Models were estimated using REML and adjusted for age and years since diagnosis (smooth terms) and for sex, education, IBD type, disease activity, and smoking status (parametric terms). Adjusted R^2 = 0.024; deviance explained = 6.65%.

Maintenance (edf = 1.37; F = 2.49; p = 0.136), Monitoring (edf = 1.00; F = 0.63; p = 0.428), and Management (edf = 1.00; F = 0.41; p = 0.523) were all non-significant. Overall model fit was poor (adjusted R^2 = −0.002; deviance explained = 3.66%).

Model-based contrasts confirmed these null findings. Moving from the 25th to the 75th percentile of SC-CII Maintenance was associated with a non-significant decrease in MCS-12 (Δ[75–25] = −1.29; 95% CI −2.79 to 0.22). Corresponding contrasts for Monitoring (Δ[75–25] = −0.51; 95% CI −1.78 to 0.75) and Management (Δ[75–25] = 0.34; 95% CI −0.71 to 1.39) were similarly non-significant. Models visualization is depicted in Figure 1.

Derivative-based analyses of the SC-CII Maintenance smooth

Given the estimated nonlinearity of the SC-CII Maintenance smooth (edf = 1.37), derivative-based analyses using simultaneous 95% confidence intervals were conducted to further characterize the shape of the association. Across the evaluated domain (Maintenance = 35.71 to 100.00), simultaneous confidence intervals for the first derivative included zero throughout, indicating no statistically supported region of monotonic increase or decrease in MCS-12 associated with Maintenance.

Figure 1 displays the partial effect plots from the DAG-adjusted GAMs. The top row depicts the smooth terms for PCS-12, and the bottom row for MCS-12. Each panel represents the partial effect of a SC-CII subscale on the outcome, adjusted for the minimal sufficient confounding set (age, sex, education, IBD type, disease activity, years since diagnosis, and smoking status). Shaded areas correspond to 95% confidence intervals. The nonlinear association between SC-CII Management and PCS-12 is visually apparent, whereas all other associations are consistent with null effects.

Table 3. Generalized additive models for MCS-12.

Associated Term	edf	F	*p*	25th percentile	75th percentile	Δ (75–25)	95% CI lower	95% CI upper
SC-CII Maintenance	1.37	2.49	0.136	60.70	78.60	−1.29	−2.79	0.22
SC-CII Monitoring	1.00	0.63	0.428	70.00	95.00	−0.51	−1.78	0.75
SC-CII Management	1.00	0.41	0.523	60.00	80.00	0.34	−0.71	1.39

Note. effective degrees of freedom for the smooth term; F = approximate F statistic for the smooth function. Models were estimated using REML and adjusted for age and years since diagnosis (smooth terms) and for sex, education, IBD type, disease activity, and smoking status (parametric terms). Adjusted R^2 = −0.002; deviance explained = 3.66%.

Covariate Associations

Associations between covariates and HRQoL outcomes are reported in Supplementary Tables S1 and S2. No covariate reached statistical significance for either PCS-12 or MCS-12 in the adjusted models, although a trend toward lower PCS-12 was observed for middle school education (estimate = −1.47; SE = 0.83; p = 0.076) and moderate disease activity showed a trend toward higher PCS-12 (estimate = 1.90; SE = 1.03; p = 0.066).

Discussion

This multicentre study examined the relationship between self-care behaviours and

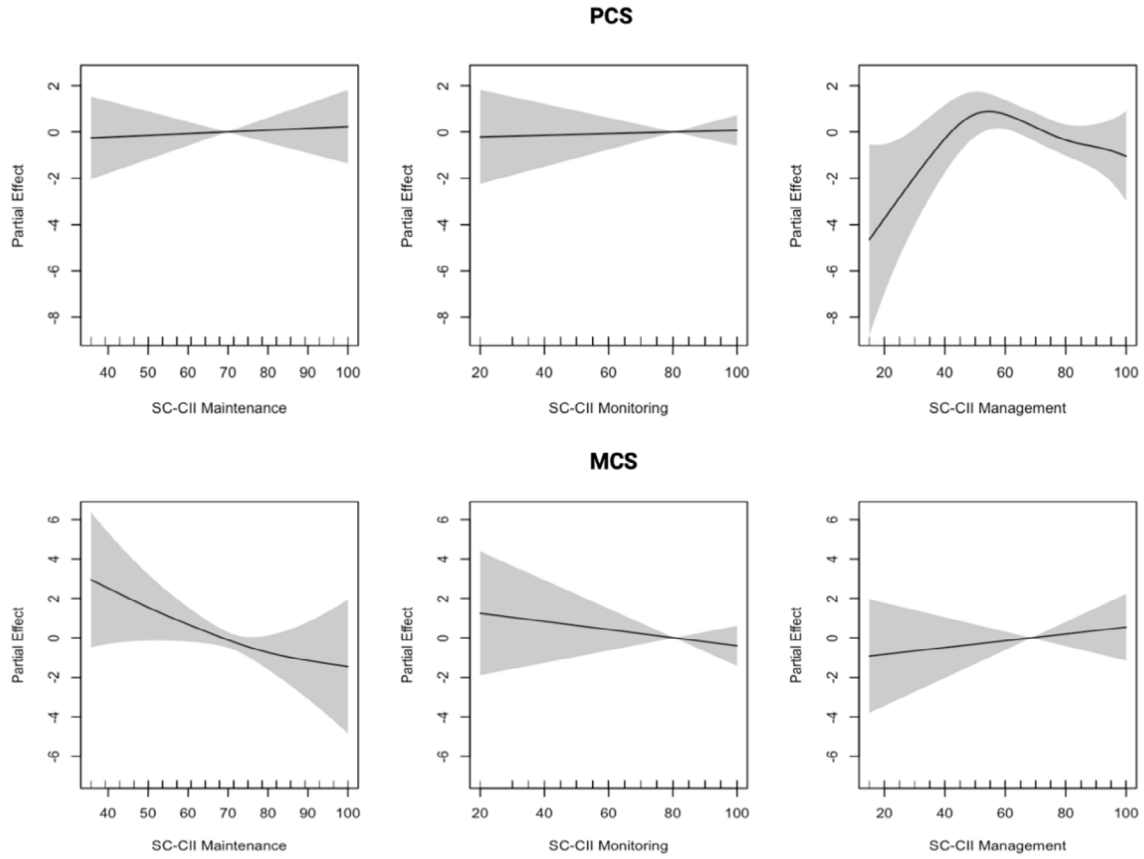


Figure 1. Partial effect plots from GAMs showing the adjusted associations between SC-CII Self-care scales and health-related quality of life outcomes (PCS-12 and MCS-12). The top row displays smooth terms for physical HRQoL (PCS-12), and the bottom row displays smooth terms for mental health (MCS-12). Each panel represents the partial effect of a SC-CII subscale on the outcome, adjusted for the minimal sufficient confounding set identified through the DAG (age, gender, education, pathology, disease activity, years since diagnosis, and smoking status). Shaded areas correspond to 95% confidence intervals. Only the SC-CII Management scale showed a statistically significant non-linear association with PCS-12, whereas no SC-CII scales demonstrated a significant association with MCS-12.

Table S1. Associations between covariates and PCS12.

Covariates	Estimate	Std. Error	p value
Gender (Male)	-0.24	0.57	0.675
Education –Primary school	-1.35	1.73	0.434
Education – High school	0.10	0.66	0.876
Education – Middle school	-1.47	0.83	0.076
Pathology – Colitis	-0.93	0.61	0.131
Disease activity – Moderate	1.90	1.03	0.066
Disease activity – Remission	1.02	0.82	0.214
Disease activity – Severe	-0.08	1.09	0.939
Smoking – Non smoker	0.15	0.70	0.831
Smoking – Smoker	-0.62	0.83	0.456

Table S2. Associations between covariates and MCS12.

Covariates	Estimate	Std. Error	p value
Intercept	37.40	1.63	<0.001
Gender (Male)	-0.01	0.88	0.995
Education – Primary school	2.65	2.66	0.320
Education – High school	-0.73	1.01	0.471
Education – Middle school	-1.06	1.28	0.406
Pathology – Colitis	1.42	0.95	0.134
Disease activity – Moderate	-1.51	1.59	0.344
Disease activity – Remission	-0.61	1.27	0.632
Disease activity – Severe	-0.79	1.68	0.636
Smoking – Non smoker	-0.33	1.08	0.763
Smoking – Smoker	-0.08	1.28	0.950

HRQoL in patients with IBD using GAMs with DAG-informed confounding adjustment. This analytical framework captures not only whether an association exists, but also how the association varies across the range of self-care behaviours, offering a more refined interpretation than traditional linear approaches.

Self-Care Behaviours and Health-Related Quality of Life in IBD

In the present sample, physical HRQoL appeared relatively preserved, whereas mental HRQoL was substantially impaired, falling nearly 13 points below the general population norm. This pattern is consistent with previous evidence demonstrating that psychological burden, including anxiety, emotional distress, and uncertainty related to disease fluctuations, plays a central role in IBD, even among patients in clinical remission (Almarzouki et al., 2024; Mules et al., 2022; Thomann et al., 2023). In an Italian cohort of IBD patients in remission, 52% reported poor HRQoL and 45% had anxiety or depression (Larussa et al., 2020). Notably, 57.2% of participants in the present study were in clinical remission, yet MCS-12 scores remained markedly low, indicating that clinical remission does not necessarily correspond to full mental health recovery (Larussa et al., 2020; Mules et al., 2022). This finding may reflect the persistence of psychological and behavioural factors beyond inflammatory disease activity, including fear of relapse, illness uncertainty, chronic fatigue, and the continuous demands of symptom monitoring, which can maintain psychological distress despite mucosal remission (Mules et al., 2022; Thomann et al., 2023; Sheehan et al., 2024; Napolitano, Bozzetti, et al., 2026).

Regarding self-care behaviours, patients demonstrated higher SC-CII Monitoring scores (80.59 ± 17.63) compared to Maintenance (69.75 ± 11.33) and Management (68.79 ± 16.75). Using the established adequacy threshold of ≥70 (Vellone, Lorini, et al., 2020), mean Maintenance and Management scores fell below the cutoff, while Monitoring exceeded it. This pattern suggests that although patients may recognize symptoms and disease changes, translating this awareness into consistent health-promoting behaviors and timely management actions remains challenging (Napolitano, Cilluffo, Amatucci, et al., 2025). Similar findings have been reported in other chronic illness populations, where self-care monitoring tends to be better developed than maintenance and management behaviours (Cai et al., 2025; Kim et al., 2026).

This imbalance between symptom recognition (monitoring) and the implementation of effective self-care behaviours (maintenance and management) may reflect multiple interacting factors that have been identified in the broader literature, including psychological distress, the unpredictable course of IBD, and differences in health literacy, access to information, and social support (Demers et al., 2025; Napolitano, Bozzetti, et al., 2026). However, these factors were not directly assessed in the present study and should therefore be considered as potential explanations rather than mechanisms supported by our data. The characteristics of the study population further help explain these findings: participants were a relatively young cohort (mean age: 43.85 years) with substantial disease experience (mean duration: 11.64 years), suggesting familiarity with disease management. However, variability in educational background, ranging from primary school (3.3%) to bachelor's degree or higher (32.5%), may have limited patients' ability to convert disease knowledge into effective self-care maintenance and management behaviours, particularly those requiring decision-making and problem-solving skills (Magi et al., 2026).

Lifestyle factors, including smoking habits, also deserve attention, as smoking is known to negatively influence disease progression and outcomes, particularly in CD (Ananthakrishnan et al., 2022). Nurse-patient mutuality has been shown to positively influence all three self-care dimensions in IBD, with distinct relational dimensions linked to distinct self-care domains, highlighting the importance of therapeutic relationships in promoting self-care (Napolitano, Bassola, et al., 2026; Napolitano, Cilluffo, Marini, et al., 2025).

Self-Care and Physical Health-Related Quality of Life

DAG-adjusted GAMs did not reveal a significant association between SC-CII Maintenance or Monitoring and PCS-12. Model-based contrasts confirmed these null findings: moving from the 25th to the 75th percentile of Maintenance was associated with a negligible change in PCS-12, and a similarly null contrast was observed for Monitoring. These results suggest that routine

self-care activities and symptom awareness, while essential for disease control, may not directly translate into perceived improvements in physical functioning. In patients with IBD, physical HRQoL is influenced by multiple factors, including disease severity, comorbidities, and long-term physiological changes, which may not be substantially modified by self-care behaviours alone (Alkrinawi et al., 2026; Larussa et al., 2020). This finding is consistent with evidence from heart failure populations, where self-care maintenance showed a modest positive association with HRQoL, but monitoring and management did not demonstrate significant associations after accounting for symptom burden (Kim et al., 2026).

In contrast, SC-CII Management showed a statistically significant nonlinear association with PCS-12. The model-based contrast revealed Management was associated with a decrease in PCS-12. This finding may reflect the reactive nature of management behaviours, which are typically activated in response to symptom exacerbations or complications (Napolitano, Cilluffo, Amatucci, et al., 2025). Therefore, higher levels of self-care management may not indicate better health status, but rather a greater need to cope with disease-related challenges. Alternatively, disease activity may lie on the pathway between self-care behaviours and physical HRQoL, although the cross-sectional nature of the present analysis does not allow this potential mediating mechanism to be established. Patients who report more intensive management behaviours may actually be those experiencing worse physical conditions, a phenomenon consistent with the concept of "confounding by indication" in observational self-care research (Napolitano, Bozzetti, et al., 2026).

This interpretation aligns with evidence from COPD dyads, where increased self-care monitoring was correlated with reduced quality of life, suggesting that heightened symptom vigilance may reflect greater disease burden rather than better outcomes (Cai et al., 2025). Similarly, in heart failure populations, monitoring and management are activated by symptom exacerbations, and accounting for disease burden may dilute positive associations between these self-care dimensions and HRQoL (Kim et al., 2026).

Overall, the weak model fit highlights the multifactorial nature of physical well-being in IBD. While self-care remains a critical component of disease management, its impact on physical outcomes may be indirect and mediated by clinical and biological factors. These findings support a broader, more integrated approach to IBD care, in which self-care support is embedded in comprehensive clinical management. Evidence from IBD medical home models demonstrates that multidisciplinary care can significantly reduce unplanned healthcare utilisation and improve both disease activity and quality of life (Regueiro et al., 2018). Similarly, the IBD BIO-ASSIST randomised controlled trial showed that IBD nurse specialists improved quality of life in patients with impaired baseline well-being on biologic therapy, providing psychosocial support, care coordination, and patient education (Bokemeyer et al., 2024). Nurse-led follow-up models have also demonstrated non-inferior and, in the social domain, clinically superior HRQoL outcomes compared to conventional care (Alvestad et al., 2022).

Self-Care and Mental Health-Related Quality of Life

DAG-adjusted GAMs did not demonstrate a meaningful association between any SC-CII domain and MCS-12. The smooth terms for Maintenance, Monitoring, and Management were all non-significant.

Rather than contradicting previous evidence, these results support the hypothesis that the relationship may operate in the opposite direction. Psychological distress has been shown to significantly influence self-care behaviours, indicating that mental health may act as a key determinant of patients' ability to engage in effective self-care (Fu et al., 2020). Fear of disease progression, a prevalent concern among IBD patients, has been shown to negatively affect HRQoL both directly and indirectly through reduced health literacy and self-care capabilities (Moradkhani et al., 2013). This suggests that improving psychological support may be essential to enhance self-care engagement, rather than expecting self-care alone to improve mental well-being.

Mental HRQoL in IBD is widely recognised as a complex and multifactorial construct, shaped by elements such as emotional distress, uncertainty related to disease course, fear of relapse, illness perception, visceral sensitivity, and the broader

psychosocial impact of living with a chronic condition (Almarzouki et al., 2024; Thomann et al., 2023). Network analysis has identified depression as the most central factor in the biopsychosocial network influencing HRQoL in IBD, with visceral sensitivity and illness identity engulfment showing the strongest direct relationships with HRQoL (Thomann et al., 2023). Perceived stress, number of relapses, and perceived social support have been identified as the strongest predictors of HRQoL in multivariate models, with psychological symptoms partially mediating the relationship between disease activity and HRQoL (Fu et al., 2020; Moradkhani et al., 2013). In this context, self-care behaviours, although essential for disease management, may not be sufficient to address the psychological burden experienced by patients.

The lack of association may also reflect a dissociation between behavioural engagement and emotional adaptation. Patients may actively engage in self-care practices while still experiencing impaired mental well-being, highlighting that adherence and self-management do not necessarily translate into psychological resilience or improved emotional outcomes (Chin et al., 2021). Self-efficacy has been shown to mediate the relationship between patient activation and daily IBD burden, with a proportion mediated of 62%, suggesting that the pathway from self-care behaviours to psychological outcomes may be substantially indirect (Tiles-Sar et al., 2025). These findings underscore the importance of integrating psychological and supportive interventions into IBD care. Integrated psychological care models have demonstrated significant improvements in anxiety, depression, and mental HRQoL in IBD patients, with in-service psychological interventions showing six-fold greater engagement compared to external referrals (Lores et al., 2019).

Limitations

First, the cross-sectional design precludes any inference regarding causality or temporal relationships between self-care behaviours and HRQoL. Although the analyses identified associations, it remains unclear whether self-care influences HRQoL, whether HRQoL affects self-care engagement, or whether both are influenced by unmeasured common causes. Although the sample size was determined a priori for the parent IBD-SELF study, it was not specifically calculated for the GAM-based secondary analyses reported here. Therefore, the possibility of limited statistical power to detect small or complex nonlinear associations cannot be completely excluded. Second, self-care and HRQoL were assessed through self-reported questionnaires. Consequently, the findings may be affected by recall bias, response bias, and social desirability bias, potentially leading to overestimation of self-care behaviours. Third, several psychosocial variables known to influence both self-care and HRQoL in IBD, such as anxiety, depression, resilience, coping strategies, self-efficacy, and social support, were not included in the analyses. Although the DAG-informed approach allowed adjustment for major sociodemographic and clinical confounders, residual confounding cannot be excluded. Moreover, although disease activity was treated as a potential confounder in the prespecified DAG, an alternative causal structure in which self-care behaviours influence disease activity, which subsequently affects HRQoL, is also theoretically plausible. Such a pathway would position disease activity as a potential mediator rather than solely as a confounder. Given the cross-sectional design, temporal ordering cannot be established and this alternative pathway could not be formally evaluated. Future longitudinal studies should therefore examine whether disease activity mediates the relationship between self-care and HRQoL. Notably, fear of disease progression, which has been shown to independently affect both self-care and HRQoL through mediating pathways involving health literacy, was not measured. Finally, participants were recruited from specialised outpatient IBD centers across Italy. Therefore, the findings may not be fully generalisable to individuals receiving care in different healthcare settings, healthcare systems, or cultural contexts.

Despite these limitations, the study benefits from a large multicentre sample (n = 453), the use of a theory-based and IBD-validated measure of self-care (SC-CII), and the application of innovative statistical approaches, including DAG-informed confounding adjustment and generalized additive modelling, providing a robust framework for investigating complex relationships between self-care and patient-reported outcomes in IBD.

Implications for Practice and Research

The findings of this study carry several implications for clinical practice and future research. First, the limited direct association between self-care behaviours and HRQoL suggests that nursing and clinical interventions should move beyond a sole focus on self-management education and incorporate strategies aimed at addressing emotional well-being, nutritional, resilience, and patient empowerment (Ribaudi et al., 2025; Said et al., 2026). IBD nurse specialists are well positioned to deliver such integrated support, as evidence demonstrates their role in improving quality of life, care coordination, and psychosocial outcomes (Bokemeyer et al., 2024; Napolitano et al., 2020, 2022; Napolitano, Scaldaferri, et al., 2025).

Future longitudinal studies are needed to clarify the causal pathways linking self-care, psychosocial determinants, and HRQoL outcomes. Mediation analyses incorporating self-efficacy, resilience, health literacy, and psychological distress as potential mediators would help elucidate the mechanisms through which self-care behaviours influence or are influenced by patient-reported outcomes. Mixed-methods designs integrating qualitative exploration of patients' lived experiences with quantitative modelling may further enrich understanding of these complex relationships.

Conclusions

This multicentre study explored the relationship between self-care behaviours and HRQoL among 453 individuals living with IBD using GAMs with DAG-informed adjustment. Despite substantially impaired mental HRQoL and suboptimal self-care Maintenance and Management scores, self-care dimensions were not meaningfully associated with MCS-12 and showed only a weak and nonlinear association with PCS-12. These results suggest that self-care behaviours alone may be insufficient to explain variations in patients' perceived well-being. HRQoL in IBD appears to be influenced by a complex interplay of clinical, psychological, and behavioural factors that extend beyond routine self-care activities. Consequently, nursing care should incorporate strategies to address emotional well-being, resilience, and patient empowerment alongside self-management support.

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References

- Alkrinawi, J., Alnees, M., Masu'd, M., Abu Hamdeh, N., Fraitekh, Y. Z., Zahran, A., Najajra, D., Darwish, A., Kabaha, A. A. R., Daoud, A., Khalil, M., Saleh, M., Barakat, M. A., Hroub, O., Abdullah, A., Qassem, Y., Majadleh, S., Abu-Khazneh, O., Khader, M., … Abu Khadija, H. (2026). Phenotype-specific determinants of health-related quality of life in Crohn's disease and ulcerative colitis: A multicenter cross-sectional study. *BMC Gastroenterology*, 26(1), 97. https://doi.org/10.1186/s12876-025-04584-6
- Almarzouki, A. F., Alluhaibi, W., Salman, B., Almuhaiyawi, M., Alreemi, M., & Alsahafi, M. (2024). The impact of cognitive functions, psychological disorders, and coping strategies on quality of life and disease outcomes in patients with inflammatory bowel diseases: A cross-sectional study. *Medicine,* 103(30), e38982. https://doi.org/10.1097/MD.0000000000038982
- Alvestad, L., Jelsness-Jørgensen, L.-P., Goll, R., Clancy, A., Gressnes, T., Valle, P. C., & Broderstad, A. R. (2022). Health-related quality of life in inflammatory bowel disease: A comparison of patients receiving nurse-led versus conventional follow-up care. *BMC Health Services Research*, 22(1), 1602. https://doi.org/10.1186/s12913-022-08985-1
- Ananthakrishnan, A. N., Kaplan, G. G., Bernstein, C. N., Burke, K. E., Lochhead, P. J., Sasson, A. N., Agrawal, M., Tiong, J. H. T., Steinberg, J., Kruis, W., Steinwurz, F., Ahuja, V., Ng, S. C., Rubin, D. T., Colombel, J.-F., Gearry, R., Abreu, M., Ahuja, V., Allez, M., … Yamamoto-Furusho, J. (2022). Lifestyle, behaviour, and environmental modification for the management of patients with inflammatory bowel diseases: An International Organization for Study of Inflammatory Bowel Diseases consensus. *The Lancet Gastroenterology & Hepatology*, 7(7), 666–678. https://doi.org/10.1016/S2468-1253(22)00021-8
- Barello, S., Guida, E., Leone, S., Previtali, E., & Graffigna, G. (2021). Does patient engagement affect IBD patients' health-related quality of life? Findings from a cross-sectional study among people with inflammatory bowel diseases. *Health and Quality of Life Outcomes,* 19(1), 77. https://doi.org/10.1186/s12955-021-01724-w
- Bokemeyer, B., Plachta-Danielzik, S., Steiner, I. M., Pohlschneider, D., Urzica, E., Hartmann, P., Zemke, J., Tappe, U., Schreiber, S., Steinkat, N., Langbrandtner, J., Hüppe, A., & Stargardt, T. (2024). Inflammatory bowel disease (IBD) patients with impaired quality of life on biologic therapy benefit from the support of an IBD nurse specialist: Results of a randomised controlled trial in Germany (IBDBIO-ASSIST study). *Alimentary Pharmacology & Therapeutics*, 59(9), 1082–1095. https://doi.org/10.1111/apt.17926
- Cai, Y., Zhang, Z., Ren, X., & Chen, O. (2025). Coping With Chronic Obstructive Pulmonary Disease Together: A Dyadic Study of Self-Care and Quality of Life in Patients and Their Caregivers. *Journal of Clinical Nursing*, 34(8), 3297–3306. https://doi.org/10.1111/jocn.17513
- Casellas, F., López-Vivancos, J., Badia, X., Vilaseca, J., & Malagelada, J.-R. (2001). Influence of inflammatory bowel disease on different dimensions of quality of life: *European Journal of Gastroenterology & Hepatology*, 13(5), 567–572. https://doi.org/10.1097/00042737-200105000-00017
- Chin, C.-H., Tseng, L.-M., Chao, T.-C., Wang, T.-J., Wu, S.-F., & Liang, S.-Y. (2021). Self-care as a mediator between symptom-management self-efficacy and quality of life in women with breast cancer. *PLOS ONE*, 16(2), e0246430. https://doi.org/10.1371/journal.pone.0246430
- Demers, K., Hendrix, E. M. B., Ardabili, A. R., Bredero, Q. M., Van Bodegraven, A. A., Van Der Horst, D., Jonkers, D. M. A. E., Kimman, M. L., Mujagic, Z., Romberg-Camps, M. J., Römkens, T. E. H., Scherpenzeel, M. P., Schroevers, M. J., Stassen, L. P. S., West, R. L., Dijkstra, G., & Pierik, M. J. (2025). Lifestyle and psychosocial factors in inflammatory bowel disease: Prevalence, impact, motivation, and support needs. *PLOS One*, 20(8), e0331092. https://doi.org/10.1371/journal.pone.0331092
- Fu, H., Kaminga, A. C., Peng, Y., Feng, T., Wang, T., Wu, X., & Yang, T. (2020). Associations between disease activity, social support and health-related quality of life in patients with inflammatory bowel diseases: The mediating role of psychological symptoms. *BMC Gastroenterology,* 20(1), 11. https://doi.org/10.1186/s12876-020-1166-y
- Harvey, R. F., & Bradshaw, J. M. (1980). A SIMPLE INDEX OF CROHN'S-DISEASE ACTIVITY. *The Lancet*, 315(8167), 514. https://doi.org/10.1016/S0140-6736(80)92767-1
- Hu, X., & Xu, L. (2024). Relationship between fear of progression and quality of life in inflammatory bowel disease: Mediating role of health literacy and self-care. *Journal of Advanced Nursing*, 80(10), 4147–4160. https://doi.org/10.1111/jan.16138
- Jakobsson, U., Westergren, A., Lindskov, S., & Hagell, P. (2012). Construct validity of the SF-12 in three different samples. *Journal of Evaluation in Clinical Practice*, 18(3), 560–566. https://doi.org/10.1111/j.1365-2753.2010.01623.x
- Kaplan, G. G., & Windsor, J. W. (2021). The four epidemiological stages in the global evolution of inflammatory bowel disease. *Nature Reviews Gastroenterology & Hepatology*, 18(1), 56–66. https://doi.org/10.1038/s41575-020-00360-x
- Kim, S. H., Lim, A., Benjasirisan, C., Himmelfarb, C. R., Davidson, P. M., Wright, R., & Koirala, B. (2026).

Relationships Among Symptom Burden, Self-Care, and Quality of Life Among Individuals Living With Heart Failure and Multimorbidity: A Cross-Sectional Study. *Journal of Clinical Nursing*, 35(7), 3098–3112. https://doi.org/10.1111/jocn.70266

- Knowles, S. R., Graff, L. A., Wilding, H., Hewitt, C., Keefer, L., & Mikocka-Walus, A. (2018). Quality of Life in Inflammatory Bowel Disease: A Systematic Review and Meta-analyses—Part I. *Inflammatory Bowel Diseases*, 24(4), 742–751. https://doi.org/10.1093/ibd/izx100
- Larussa, T., Flauti, D., Abenavoli, L., Boccuto, L., Suraci, E., Marasco, R., Imeneo, M., & Luzza, F. (2020). The Reality of Patient-Reported Outcomes of Health-Related Quality of Life in an Italian Cohort of Patients with Inflammatory Bowel Disease: Results from a Cross-Sectional Study. *Journal of Clinical Medicine*, 9(8), 2416. https://doi.org/10.3390/jcm9082416
- Lewis, J. D., Chuai, S., Nessel, L., Lichtenstein, G. R., Aberra, F. N., & Ellenberg, J. H. (2008). Use of the noninvasive components of the mayo score to assess clinical response in Ulcerative Colitis: *Inflammatory Bowel Diseases*, 14(12), 1660–1666. https://doi.org/10.1002/ibd.20520
- Ling, F., Tu, L., Li, J., Chen, Y., Xu, M., & Zhu, L. (2021). Psychological aspect of patients with inflammatory bowel disease, which may be related to the quality of life, sleep and disease characteristics. Scandinavian *Journal of Gastroenterology*, 56(11), 1328–1336. https://doi.org/10.1080/00365521.2021.1966093
- Lores, T., Goess, C., Mikocka-Walus, A., Collins, K. L., Burke, A. L. J., Chur-Hansen, A., Delfabbro, P., & Andrews, J. M. (2019). Integrated Psychological Care is Needed, Welcomed and Effective in Ambulatory Inflammatory Bowel Disease Management: Evaluation of a New Initiative. *Journal of Crohn's and Colitis*, 13(7), 819–827. https://doi.org/10.1093/ecco-jcc/jjz026
- Lovén Wickman, U., Yngman-Uhlin, P., Hjortswang, H., Wenemark, M., Stjernman, H., Riegel, B., & Hollman Frisman, G. (2019). Development of a self-care questionnaire for clinical assessment of self-care in patients with inflammatory bowel disease: A psychometric evaluation. *International Journal of Nursing Studies*, 89, 1–7. https://doi.org/10.1016/j.ijnurstu.2018.08.016
- Magi, C. E., El Aoufy, K., Amato, C., Longobucco, Y., Bambi, S., Vellone, E., Bonaccorsi, G., Lorini, C., Rasero, L., & Iovino, P. (2026). The Association Between Self-Care and Health Literacy in Patients With Chronic Diseases: A Systematic Review and Meta-Analysis. *Journal of Clinical Nursing*, 35(7), 3011–3029. https://doi.org/10.1111/jocn.70291
- Moradkhani, A., Beckman, L. J., & Tabibian, J. H. (2013). Health-related quality of life in inflammatory bowel disease: Psychosocial, clinical, socioeconomic, and demographic predictors. *Journal of Crohn's and Colitis*, 7(6), 467–473. https://doi.org/10.1016/j.crohns.2012.07.012
- Mules, T. C., Swaminathan, A., Hirschfeld, E., Borichevsky, G., Frampton, C., Day, A. S., & Gearry, R. B. (2022). The impact of disease activity on psychological symptoms and quality of life in patients with inflammatory bowel disease—Results from the Stress, Anxiety and Depression with Disease Activity (SADD) Study. *Alimentary Pharmacology & Therapeutics*, 55(2), 201–211. https://doi.org/10.1111/apt.16616
- Napolitano, D., Bassola, B., Lusignani, M., & Cilluffo, S. (2026). The Role of Nurse–Patient Mutuality on Self-Care Behaviors in Adults Living with Inflammatory Bowel Disease: A Multicenter Cross-Sectional Study. *Digestive Diseases and Sciences*. https://doi.org/10.1007/s10620-026-09883-w
- Napolitano, D., Biagioli, V., Bartoli, D., Cilluffo, S., Martella, P., Monaci, A., Vellone, E., & Cocchieri, A. (2025). Validity and Reliability of the Self-Care of Chronic Illness Inventory in Patients Living With Inflammatory Bowel Disease. *Journal of Clinical Nursing*, 34(11), 4642–4653. https://doi.org/10.1111/jocn.17712
- Napolitano, D., Bozzetti, M., Amato, S., Genna, C., Thekkan, K. R., Benedetti, F., Petruccini, G., Petralito, M., Milani, I., & Caruso, R. (2026). Theories and determinants of self-care and self-efficacy in inflammatory bowel diseases: A systematic review. *Patient Education and Counseling*, 150, 109717. https://doi.org/10.1016/j.pec.2026.109717
- Napolitano, D., Bozzetti, M., Lo Cascio, A., De Stefano, G., Orgiana, N., Lopetuso, L. R., D'Onofrio, A. M., Camardese, G., Papa, A., Scaldaferri, F., Cocchieri, A., & Bartoli, D. (2025). Resilience and Self-Care in Patients with Inflammatory Bowel Disease: A Multicentre Cross-Sectional Study in Outpatient Settings. *Journal of Clinical Medicine*, 14(11), 3868. https://doi.org/10.3390/jcm14113868
- Napolitano, D., Cilluffo, S., Amatucci, V., Bartoli, D., Biagioli, V., Martella, P., Monaci, A., Cocchieri, A., & Vellone, E. (2025). Self-Care in Patients With Inflammatory Bowel Disease: A Descriptive Cross-Sectional Multicenter Study. *Crohn's & Colitis 360*, 7(4), otaf061. https://doi.org/10.1093/crocol/otaf061
- Napolitano, D., Cilluffo, S., Marini, A., & Lusignani, M. (2025). Exploring nurse–patient mutuality in inflammatory bowel disease: A multicenter cross-sectional study. *BMC Nursing*, 25(1), 59. https://doi.org/10.1186/s12912-025-04215-1
- Napolitano, D., Martella, P., Schiavoni, E., Turchini, L., Amatucci, V., Armuzzi, A., Cocchieri, A., Zega, M., Scaldaferri, F., & Gasbarrini, A. (2020). The awareness of the IBD nurse position among patients from an Italian tertiary IBD centre. *Professioni Infermieristiche*, 73(3), 213–218. https://doi.org/10.7429/pi.2020.733213
- Napolitano, D., Scaldaferri, F., Leone, S., Previtali, E., Fiorino, G., Caprioli, F., Fantini, M. C., Radice, S., Lorenzon, G., Schiavoni, E., & Nurse IGIBD Group. (2025). The Dedicated Inflammatory Bowel Disease

Nurse, If You Know Them, You Love Them: Survey of the Italian IBD Patients' Association. *Crohn's & Colitis 360*, 7(4), otaf063. https://doi.org/10.1093/crocol/otaf063
- Napolitano, D., Schiavoni, E., & Scaldaferri, F. (2022). Nurse Practitioners in Inflammatory Bowel Disease: The Emerging Role of the IBD Care Manager. *Journal of Gastrointestinal and Liver Diseases*, 31(4), 4627. https://doi.org/10.15403/jgld-4627
- Napolitano, D., Vellone, E., Iovino, P., Scaldaferri, F., & Cocchieri, A. (2024). Self-care in patients affected by inflammatory bowel disease and caregiver contribution to self-care (IBD-SELF): A protocol for a longitudinal observational study. *BMJ Open Gastroenterology*, 11(1), e001510. https://doi.org/10.1136/bmjgast-2024-001510
- Ng, S. C., Shi, H. Y., Hamidi, N., Underwood, F. E., Tang, W., Benchimol, E. I., Panaccione, R., Ghosh, S., Wu, J. C. Y., Chan, F. K. L., Sung, J. J. Y., & Kaplan, G. G. (2017). Worldwide incidence and prevalence of inflammatory bowel disease in the 21st century: A systematic review of population-based studies. *The Lancet*, 390(10114), 2769–2778. https://doi.org/10.1016/S0140-6736(17)32448-0
- Papp-Zipernovszky, O., Horvát, B., Dávid, A., Rafael, B., Tóth-Njers, S., Strausz, D., Gyóllai, M., Molnár, T., Sallay, V., Konkolÿ Thege, B., & Martos, T. (2026). Is (critical) health literacy a key to better psychosomatic functioning in patients with inflammatory bowel disease? Testing a mediation model. *Frontiers in Psychiatry*, 17, 1643641. https://doi.org/10.3389/fpsyt.2026.1643641
- Peters, M., Potter, C. M., Kelly, L., & Fitzpatrick, R. (2019). Self-efficacy and health-related quality of life: A cross-sectional study of primary care patients with multi-morbidity. *Health and Quality of Life Outcomes*, 17(1), 37. https://doi.org/10.1186/s12955-019-1103-3
- R Core Team. (2023). *R: A language and environment for statistical computing [Software]*. R Foundation for Statistical Computing. https://www.R-project.org/
- Regueiro, M., Click, B., Anderson, A., Shrank, W., Kogan, J., McAnallen, S., & Szigethy, E. (2018). Reduced Unplanned Care and Disease Activity and Increased Quality of Life After Patient Enrollment in an Inflammatory Bowel Disease Medical Home. *Clinical Gastroenterology and Hepatology*, 16(11), 1777–1785. https://doi.org/10.1016/j.cgh.2018.04.007
- Ribaudi, E., Amato, S., Becherucci, G., Carillo, S., Covello, C., Mora, V., Mentella, M. C., Scaldaferri, F., Gasbarrini, A., Fanali, C., Laterza, L., & Napolitano, D. (2025). Addressing Nutritional Knowledge Gaps in Inflammatory Bowel Disease: A Scoping Review. *Nutrients*. https://doi.org/10.3390/nu17050833
- Riegel, B., Barbaranelli, C., Sethares, K. A., Daus, M., Moser, D. K., Miller, J. L., Haedtke, C. A., Feinberg, J. L., Lee, S., Stromberg, A., & Jaarsma, T. (2018). Development and initial testing of the self-care of chronic illness inventory. *Journal of Advanced Nursing*, 74(10), 2465–2476. https://doi.org/10.1111/jan.13775
- Riegel, B., Jaarsma, T., & Strömberg, A. (2012). A Middle-Range Theory of Self-Care of Chronic Illness. *Advances in Nursing Science*, 35(3), 194–204. https://doi.org/10.1097/ANS.0b013e318261b1ba
- Said, H., Moulton, C. D., Hart, A., & Keefer, L. (2026). Holistic care in inflammatory bowel disease: Is it in REACH? *Journal of Crohn's and Colitis*, 20(Supplement_2), ii52–ii65. https://doi.org/10.1093/ecco-jcc/jjaf227
- Sheehan, J. L., Greene-Higgs, L., Resnicow, K., Patel, M. R., Barnes, E. L., Waljee, A. K., Higgins, P. D. R., & Cohen-Mekelburg, S. (2024). Self-Efficacy, Patient Activation, and the Burden of Inflammatory Bowel Disease on Patients' Daily Lives. *Digestive Diseases and Sciences*, 69(11), 4089–4097. https://doi.org/10.1007/s10620-024-08712-2
- Stone, J. K., Shafer, L. A., Graff, L. A., Witges, K., Sexton, K., Lix, L. M., Haviva, C., Targownik, L. E., & Bernstein, C. N. (2022). The association of efficacy, optimism, uncertainty and health anxiety with inflammatory bowel disease activity. *Journal of Psychosomatic Research*, 154, 110719. https://doi.org/10.1016/j.jpsychores.2022.110719
- Textor, J., Hardt, J., & Knüppel, S. (2011). DAGitty: A Graphical Tool for Analyzing Causal Diagrams. *Epidemiology*, 22(5), 745. https://doi.org/10.1097/EDE.0b013e318225c2be
- Thomann, A. K., Knödler, L.-L., Karthikeyan, S., Atanasova, K., Bernstein, C. N., Ebert, M. P., Lis, S., & Reindl, W. (2023). The Interplay of Biopsychosocial Factors and Quality of Life in Inflammatory Bowel Diseases: A Network Analysis. *Journal of Clinical Gastroenterology*, 57(1), 57–65. https://doi.org/10.1097/MCG.0000000000001625
- Tiles-Sar, N., Neuser, J., De Sordi, D., Baltes, A., Preiss, J. C., Moser, G., & Timmer, A. (2025). Psychological interventions for treatment of inflammatory bowel disease. *Cochrane Database of Systematic Reviews*, 2025(4). https://doi.org/10.1002/14651858.CD006913.pub3
- Tormey, L. K., Reich, J., Chen, Y. S., Singh, A., Lipkin-Moore, Z., Yu, A., Weinberg, J., Farraye, F. A., & Paasche-Orlow, M. K. (2019). Limited Health Literacy Is Associated With Worse Patient-Reported Outcomes in Inflammatory Bowel Disease. *Inflammatory Bowel Diseases*, 25(1), 204–212. https://doi.org/10.1093/ibd/izy237
- Vellone, E., Barbaranelli, C., Pucciarelli, G., Zeffiro, V., Alvaro, R., & Riegel, B. (2020). Validity and Reliability of the Caregiver Contribution to Self-Care of Heart Failure Index Version 2. *Journal of Cardiovascular Nursing*, 35(3), 280–290. https://doi.org/10.1097/JCN.0000000000000655
- Vellone, E., Lorini, S., Ausili, D., Alvaro, R., Di Mauro, S., De Marinis, M. G., Matarese, M., & De Maria, M.

(2020). Psychometric characteristics of the caregiver contribution to self-care of chronic illness inventory. *Journal of Advanced Nursing*, 76(9), 2434–2445. https://doi.org/10.1111/jan.14448

- von Elm, E., Altman, D. G., Egger, M., Pocock, S. J., Gøtzsche, P. C., Vandenbroucke, J. P., & STROBE Initiative. (2008). The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: Guidelines for reporting observational studies. *Journal of Clinical Epidemiology*, 61(4), 344–349. https://doi.org/10.1016/j.jclinepi.2007.11.008
- Wang, H., Ding, J., Liu, G., Sun, G., Zhang, X., Xiao, W., Cai, Y., & Lin, A. (2025). Efficacy of different psychological interventions for the treatment of inflammatory bowel disease: A systematic review and network meta-analysis. *Frontiers in Medicine*, 12, 1630034. https://doi.org/10.3389/fmed.2025.1630034
- Ware, J. E., Kosinski, M., & Keller, S. D. (1996). A 12-Item Short-Form Health Survey: Construction of Scales and Preliminary Tests of Reliability and Validity. *Medical Care*, 34(3), 220–233. https://doi.org/10.1097/00005650-199603000-00003
- Whelan, K., Murrells, T., Morgan, M., Cummings, F., Stansfield, C., Todd, A., Sebastian, S., Lobo, A., Lomer, M. C., Lindsay, J. O., & Czuber-Dochan, W. (2021). Food-related quality of life is impaired in inflammatory bowel disease and associated with reduced intake of key nutrients. *The American Journal of Clinical Nutrition*, 113(4), 832–844. https://doi.org/10.1093/ajcn/nqaa395
- Zhang, C. K., Hewett, J., Hemming, J., Grant, T., Zhao, H., Abraham, C., Oikonomou, I., Kanakia, M., Cho, J. H., & Proctor, D. D. (2013). The Influence of Depression on Quality of Life in Patients with Inflammatory Bowel Disease: *Inflammatory Bowel Diseases*, 19(8), 1732–1739. https://doi.org/10.1097/MIB.0b013e318281f395