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Predictors of self-care among informal caregivers of patients with inflammatory bowel disease: a cross-sectional study

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Abstract

Background Informal caregivers of individuals with inflammatory bowel disease (IBD) face unpredictable responsibilities that may compromise their health. While caregiver burden and psychological distress are well-documented, little is known about caregivers' self-care practices and their determinants.

Methods A multicenter cross-sectional study was conducted across 9 Italian IBD Units between April and June 2024. Caregivers completed validated measures of self-care (Self-Care of Informal Caregivers Inventory), caregiver burden (Zarit Burden Interview), and psychological distress (Depression Anxiety Stress Scales–21). Logistic regression models were used to identify predictors of inadequate self-care behaviors.

Results A total of 229 caregivers were included (mean age 52.2±13.6 years; 59% women). Adequate self-care was high for routine behaviors such as daily hygiene (98.7%) and regular meals (87.8%), but low for emotionally and socially demanding behaviors, including professional counseling (18.3%), asking for assistance (12.2%), and accepting help (20.6%). Being unpartnered was associated with a higher likelihood of inadequate physical activity (odds ratio [OR] 2.38, 95% confidence interval [CI] 1.32-4.17). Higher anxiety was related to inadequate attention to bodily discomfort (OR 1.32, 95%CI 1.11-1.56), whereas higher caregiver burden and depression were associated with a lower likelihood of inadequate emotional wellbeing strategies (OR 0.97, 95%CI 0.95-0.99), and inadequate help-seeking (OR 0.80, 95%CI 0.68-0.93), respectively.

Conclusions Caregivers maintain basic health habits but show marked vulnerabilities in emotional and social self-care domains. Psychological distress and relational factors play a key role, underscoring the need for caregiver-centered interventions that promote emotional wellbeing, resilience, and help-seeking.

Keywords Caregiver burden, caregiving relationships, inflammatory bowel disease, psychological distress, self-care

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Conflict of Interest: None

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Introduction

Inflammatory bowel disease (IBD) poses unique challenges for both patients and caregivers, due to their fluctuating course, need for constant vigilance, and potentially stigmatizing symptoms, such as fecal urgency and incontinence [1]. For caregivers, these challenges translate into continuous involvement in daily care, ranging from medical coordination to emotional support, often without formal training or adequate resources [2]. The unpredictable relapses and stigmatizing symptoms of IBD intensify psychological strain and limit social participation, profoundly affecting both

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patients and their informal caregivers [3,4]. As a result, caregiving responsibilities frequently extend beyond clinical support, and profoundly shape caregivers' daily lives, routines and psychosocial wellbeing. Although caregiver-centered research has increasingly focused on burden and psychological distress, limited attention has been paid to how caregivers of individuals with IBD sustain their own health and engage in self-care behaviors [5,6].

Grounded in the middle-range theory of self-care of chronic illness [7], self-care refers to a proactive, multidimensional process encompassing self-care maintenance, monitoring, and management. However, many caregivers supporting individuals with unpredictable and stigmatized diseases like IBD struggle to engage in adequate self-care, because of psychological overload, time constraints, and low self-efficacy [8-10].

IBD, including Crohn's disease (CD) and ulcerative colitis (UC), is a chronic, immune-mediated condition with a fluctuating course, characterized by alternating periods of remission and relapse. These phases often involve multiple symptoms requiring hospitalization, surgical interventions and lifestyle adjustments [11-13]. Beyond their physical manifestations, IBD is frequently stigmatized because of their intimate and socially taboo symptoms, adding a psychosocial burden that can limit social participation and impair quality of life. During flares, caregivers assist with symptom management and hospital-related care [14-18]. Even in remission, the persistent threat of relapse contributes to chronic stress and uncertainty [16,19-22].

The burden of caregiving intensifies when disease activity is high, the patient is younger, or cohabitation is involved [6]. Spousal or live-in caregivers are particularly vulnerable to emotional exhaustion due to the overlap of personal and caregiving responsibilities [23]. High care demands, especially for physically and emotionally taxing tasks, are linked to increased anxiety, depression and burnout [24]. Social withdrawal, often stemming from the patient's reduced public engagement, can further erode coping resources [24,25]. Despite these challenges, informal caregivers frequently remain under-recognized, excluded from decision-making, and without structured training or psychosocial support, leading to cumulative distress and potentially compromising the sustainability of care [15,16,23].

Despite the recognition of stress, anxiety, depression and burnout among IBD caregivers, few studies have investigated how they maintain health and engage in self-care, since most research focuses on burden or mental health outcomes [26,27]. While self-care is widely acknowledged as central to chronic illness management in patients, it remains underexplored and poorly operationalized in caregiver populations [28]. This gap is particularly relevant in IBD, where caregiving is characterized by unpredictability, stigma, and minimal formal support [6,29,30].

Moreover, caregiver self-care is often described broadly, rather than as a set of behaviors shaped by psychological, relational and contextual factors. No studies have systematically investigated self-care among IBD caregivers, nor identified at-risk domains or psychosocial variables associated with inadequate self-care. Addressing this gap is essential to designing support strategies that reduce psychological burden and promote sustainable caregiving, benefiting both caregivers and patients. The specific aim of this study was to identify patterns of adequate and inadequate self-care behaviors and to examine the sociodemographic, relational, and psychological factors predicting these behaviors among informal caregivers of IBD patients.

Materials and methods

Study design and setting

This was a multicenter cross-sectional study conducted between April and June 2024 across 9 Italian IBD Units distributed throughout different geographical areas of Italy (north, center, and south) [31]. The multicenter design and consecutive recruitment across heterogeneous clinical settings were intended to enhance sample heterogeneity and reduce selection bias. The study followed the STROBE guidelines for observational research.

Participants

Eligible participants were caregivers of adult patients diagnosed with IBD. Inclusion criteria were: (a) age ≥18 years; (b) active involvement in informal caregiving for at least 6 months for IBD patients; and (c) ability to understand and complete the questionnaire. At each IBD Unit, caregivers were identified by the local IBD Units team and approached in person by trained healthcare professionals (IBD nurses or gastroenterologists). Participants were identified and recruited consecutively during routine outpatient visits or scheduled clinical follow-ups. A total of 229 caregivers completed the survey; the anonymous recruitment procedure meant that detailed data on the number of eligible caregivers approached or declining participation was not systematically collected.

Measures

Sociodemographic and clinical data

Caregivers completed a structured questionnaire containing sociodemographic and caregiving-related variables, including

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age, sex, education, occupational status, relationship with the patient, duration of caregiving, and presence of minor children. They also rated their perceived care load on a 4-level scale (light, manageable, heavy, very heavy) and reported their area of residence (north, center, south). Patient diagnosis and disease activity (remission vs. active disease) were obtained from medical records.

Self-care of informal caregiver inventory (SC-ICI)

Caregiver self-care behaviors were assessed using the SC-ICI [23], designed to capture physical, emotional and behavioral aspects of self-care. The SC-ICI is grounded in the middle-range theory of self-care [7], encompassing 3 dimensions: self-care maintenance, self-care monitoring, and self-care management. The final version consists of 27 items rated on a 5-point Likert scale (1 = Never to 5 = Always) and is structured according to the theoretical domains of self-care maintenance, self-care monitoring, and self-care management, encompassing behaviors such as adherence to healthy habits, attention to symptoms and distress, and the implementation of coping and response strategies. Before its use with Italian IBD caregivers, the SC-ICI underwent translation, back-translation and a cognitive interview with 15 caregivers.

Caregiver burden

To evaluate perceived caregiver burden, the Zarit Burden Interview (ZBI) was administered [32]. The ZBI is widely used among informal caregivers of people with chronic illness and assesses emotional, physical, social, and financial strain, including personal and role-related strain. It consists of 22 items rated on a 5-point Likert scale, with higher scores indicating greater burden. The instrument demonstrates high internal consistency (Cronbach's α>0.85), good test–retest reliability, and strong construct validity [33,34]. The Italian version showed excellent psychometric properties, including high internal consistency (Cronbach's α=0.89), factorial validity and concurrent validity with psychological distress measures [35].

Psychological distress

Psychological distress in caregivers was assessed using the Depression Anxiety Stress Scales-21 (DASS-21) [36], a widely used self-reporting questionnaire measuring depression, anxiety and stress. The DASS-21 consists of 21 items (7 per subscale) rated on a 4-point Likert scale. Subscale scores are summed and multiplied by 2 for comparability with the original 42-item version. The instrument has high internal consistency (Cronbach's α>0.85) and strong construct and convergent validity [37]. The Italian version confirmed the 3-factor structure and demonstrated good reliability (α=0.90 for depression, 0.82 for anxiety, 0.86 for stress) and validity [38].

Statistical analysis

Statistical analysis was conducted using SPSS version 25 (IBM Corp., Armonk, NY). Descriptive statistics were calculated; continuous variables are reported as mean ± standard deviation (SD) and categorical variables as n (%). To identify the most problematic self-care behaviors among caregivers, responses to the 27 SC-ICI items (5-point Likert scale) were dichotomized as "adequate" (scores 4-5) or "not adequate" (scores 1-3). This decision was guided primarily by the semantic meaning of the Likert scale labels in the SC-ICI, where "often" and "always" intuitively reflect adequate self-care, whereas responses from "sometimes" to "never" suggest inadequate self-care. This approach is consistent with a prior study on self-care [39]. Item-level results are therefore reported as the proportion of responses in the "often/always" range (scores 4-5). For each item, we calculated the proportion of adequate responses, along with its 95% confidence interval (CI), using the Wilson score method [40]. The use of the CI allowed us to account for sampling variability and avoid misclassifying items as "adequate" when the observed proportion was borderline. We considered an item critical when the upper bound of its 95%CI was below the 70% adequacy threshold commonly adopted in self-care research [41]. This conservative rule ensured that only behaviors with robust evidence of inadequate performance were flagged.

Among these critical items, we further prioritized those representing the largest burden of inadequate self-care. Specifically, items were ranked by the absolute number of inadequate responses (scores 1-3). Following the Pareto principle [42], we then calculated the cumulative percentage of all non-adequate responses and retained only the subset of items that together accounted for about 60% of the overall inadequacy. This procedure allowed us to focus on a smaller set of key behaviors that contribute most to inadequate self-care, making the results easier to interpret and more relevant for targeting future interventions. In total, the following 11 items met these criteria: do physical activities (self-care maintenance); monitor your weight, pay attention to signs of being overwhelmed, pay attention to signs of fatigue, and pay attention to signs of discomfort (self-care monitoring); change caregiving efforts based on physical status, increase regular sports activities, adopt techniques to enhance your emotional wellbeing, seek professional counseling/support group, ask for assistance from others, and accept help from others (self-care management).

Finally, each of the 11 binary outcomes (adequate vs. non-adequate behavior) was modeled using logistic regression. Nine predictors were chosen *a priori* (depression, anxiety, stress, caregiver burden, age, sex, patient relationship, disease stage) guided by theoretical frameworks and empirical evidence from chronic-condition caregiving/self-care research [7,43]. Categorical predictors were entered as indicator variables (reference = first category). Sex was coded as female = 1 (male = 0); caregiving relationship as married/partnered = 1 (not married/partnered = 0); and disease activity as active disease = 1 (remission = 0). For each model, we reported odds ratios (OR) with 95%CI. To account for multiple comparisons across the 11 outcomes, P-values were adjusted using the Bonferroni method (α_corr = 0.05/11 = 0.0045; p_Bonf = min[1, p × 11]). Linearity in the logit was checked for all continuous predictors (age, burden, depression, anxiety, stress) using the Box–Tidwell approach (x·ln x terms); no significant departures were observed. Multicollinearity was assessed with variance inflation factors (all VIFs <2.5). Eventspervariable (EPV) were ≥10 in every model (minimum EPV=28); therefore, model estimates were considered stable. No formal *a priori* power calculation was performed, because the study was exploratory and observational. Sample adequacy was evaluated based on the EPV criterion for logistic regression models, which was met in all analyses.

Although consecutive multicenter recruitment was adopted, a potential risk of nonresponse bias cannot be entirely ruled out, as information on non-responders was not available. Missing data were minimal across study variables (all <5%). Therefore, analyses were performed using a complete-case approach. As a result, the effective sample size contributing to each regression model varied only marginally and remained close to the full cohort (N≈220) across all analyses. Given the low proportion of missingness, the cross-sectional design and the focus on item-level self-care behaviors, multiple imputation was not deemed necessary.

Ethical considerations

The study complied with Good Clinical Practice and the Declaration of Helsinki. Ethical approval was obtained from the Territorial Ethics Committee (Approval ID: 0023486/23) on August 2, 2023, and the protocol was registered on ClinicalTrials.gov (Identifier: NCT06015789). Participants provided informed consent, participation was voluntary, and confidentiality and the right to withdraw at any time were ensured.

Results

Sample characteristics

The study included 229 informal caregivers, equally divided between those supporting individuals with CD (n=115) and UC (n=114). The mean age was 52 years, and 59% were women. Most were married or partnered (85%), employed (65%), and had completed at least upper secondary education (49%). Nearly half had been providing care for more than 5 years, most often as a spouse (49%) or parent (16%) of the patient. The majority described their care load as light to manageable (63%), though about 1 in 5 (20%) reported it as very heavy. Caregivers were distributed across Italy, with a large proportion living in the north (Table 1).

Table 1 Sociodemographic and caregiving characteristics of the sample (N=229)

Variable	Mean±SD or n (%)
Age (years)	52.2±13.55
Sex	
Female	135 (59.0)
Male	94 (41.0)
Education	
Up to primary school	6 (2.6)
Lower secondary school	54 (23.6)
Upper secondary school	111 (48.5)
University degree or higher	58 (25.3)
Occupation	
Employed	149 (65.1)
Student	4 (1.7)
Unemployed	8 (3.5)
Retired	43 (18.8)
Homemaker	25 (10.9)
Minor children (<18)	
Yes	50 (21.8)
No	179 (78.2)
Marital status	
Single	17 (7.2)
Married/partnered	194 (84.8)
Divorced	15 (6.6)
Widowed	3 (1.3)
Relationship with patient	
None	19 (8.3)
Spouse	113 (49.3)
Parent	37 (16.2)
Sibling	4 (1.7)
Partner	11 (4.8)
Relative	20 (8.7)
Son/daughter in law	25 (10.9)
Time as caregiver (over 5 years)	104±45.4
Care load	
Light	67 (29.3)
Manageable	76 (33.2)
Heavy	41 (17.9)
Very heavy	45 (19.7)
Residence	
North	103 (45.0)
Centre	61 (26.6)
South	65 (28.4)
Caregiver burden (ZBI)	18.05±14.56
Depression (DASS)	4.56±3.56
Anxiety (DASS)	4.05±2.96
Stress (DASS)	6.62±3.93)
Disease activity	
Remission	126 (55.0)
Active	103 (45.0)

Values are mean ± standard deviation (SD) for continuous variables and n (%) for categorical variables

Regarding psychological and caregiving-related measures, the mean caregiver burden, as measured by the ZBI, was 18.05±14.56 indicating a low to mild level of burden according to established cut-offs. On the DASS-21, the mean depression score was 4.56±3.56, the mean anxiety score was 4.05±2.96, and the mean stress score was 6.62±3.93 all of which fall within the normal range based on standard severity classifications. Based on medical records, 55.0% of patients were classified as in remission, while 45.0% had active disease at the time of assessment.

Self-care behaviors

Table 2 presents the mean item scores for each SC-ICI scale, which collectively reflect moderate to high engagement in self-care behaviors. Most items showed mean values above 3, indicating that they were "sometimes" or "often" engaged in the given behavior.

Regarding the self-care maintenance scale, the highest mean scores were observed for "Maintain daily personal hygiene" (4.58±0.52) and "Eat all the essential meals of the day" (4.34±0.76), suggesting that these activities were performed "often" to "always" by the majority of caregivers.

Table 2 Item-level descriptive statistics of the self-care inventory for informal caregivers of IBD patients (n=229)

	Item	Mean±SD	Never, n (%)	Rarely (%)	Sometimes (%)	Often (%)	Always (%)
	Self-care maintenance						
1	Maintain daily personal hygiene	4.58±0.52	-	-	3 (1.3)	91 (39.7)	135 (59.0)
2	Do physical activities	2.98±1.21	25 (10.9)	70 (30.6)	44 (19.2)	65 (28.4)	25 (10.9)
3	Eat all the essential meals of the day	4.34±0.76	-	6 (2.6)	22 (9.6)	90 (39.3)	111 (48.5)
4	Keep a healthy, balanced diet	3.86±0.89	-	14 (6.1)	66 (28.8)	87 (38.0)	62 (27.1)
5	Drink enough water	3.87±0.88	1 (0.4)	12 (5.2)	63 (27.5)	92 (40.2)	61 (26.6)
6	Avoid smoking or vaping	4.39±1.16	12 (5.2)	8 (3.5)	30 (13.1)	7 (3.1)	172 (75.1)
7	Avoid or limit alcohol intake daily	4.10±0.96	5 (2.2)	10 (4.4)	36 (15.7)	85 (37.1)	93 (40.6)
8	Make sure to get enough sleep during the night	3.34±1.02	9 (3.9)	44 (19.2)	59 (25.8)	95 (41.5)	22 (9.6)
9	If/when prescribed, take the medications or supplements on time	3.72±1.20	20 (8.7)	9 (3.9)	56 (24.5)	73 (31.9)	71 (31.0)
10	Give yourself a break and make time to relax	3.21±1.00	14 (6.1)	40 (17.5)	72 (31.4)	90 (39.3)	13 (5.7)
11	Keep contact with friends and engage in social activities	3.54±0.93	8 (3.5)	16 (7.0)	79 (34.5)	96 (41.9)	30 (13.1)
	Self-care monitoring						
12	Monitor your physical health	3.43±0.99	9 (3.9)	34 (14.8)	58 (25.3)	105 (45.9)	23 (10.0)
13	Monitor your weight	3.04±0.84	14 (6.1)	23 (10.0)	145 (63.3)	35 (15.3)	12 (5.2)
14	Monitor your daily eating habits	3.45±0.86	7 (3.1)	10 (4.4)	112 (48.9)	74 (32.3)	26 (11.4)
15	Pay attention to your emotional state	3.32±0.97	4 (1.7)	42 (18.3)	87 (38.0)	68 (29.7)	28 (12.2)
16	Pay attention to signs of being overwhelmed	2.78±1.04	33 (14.4)	47 (20.5)	98 (42.8)	41 (17.9)	10 (4.4)
17	Pay attention to signs of fatigue	2.93±1.04	21 (9.2)	47 (20.5)	109 (47.6)	30 (13.1)	22 (9.6)
18	Pay attention to signs of discomfort	2.97±0.95	16 (7.0)	44 (19.2)	113 (49.3)	42 (18.3)	14 (6.1)
	Self-care management						
19	Change your caregiving efforts based on your physical status	2.73±1.02	25 (10.9)	76 (33.2)	70 (30.6)	51 (22.3)	7 (3.1)
20	Avoid or limit unhealthy snacks, meals, and drinks	3.37±1.09	14 (6.1)	35 (15.3)	64 (27.9)	84 (36.7)	32 (14.0)
21	Increase regular sports activities	2.97±0.89	9 (3.9)	59 (25.8)	102 (44.5)	50 (21.8)	9 (3.9)
22	Adopt techniques to enhance your emotional wellbeing	3.07±1.06	23 (10.0)	39 (17.0)	79 (34.5)	75 (32.8)	13 (5.7)
23	Find harmony and balance between your personal life, work, and caregiving roles	3.26±1.08	22 (9.6)	29 (12.7)	62 (27.1)	100 (43.7)	16 (7.0)
24	Change your sleep habits	3.38±1.02	13 (5.7)	29 (12.7)	68 (29.7)	96 (41.9)	23 (10.0)
25	Seek professional counseling or join support groups	2.15±1.23	94 (41.0)	59 (25.8)	34 (14.8)	31 (13.5)	11 (4.8)
26	Ask for assistance from others	2.38±1.06	55 (24)	70 (30.6)	76 (33.2)	19 (8.3)	9 (3.9)
27	Accept help from others	2.66±1.19	46 (20.1)	53 (23.1)	83 (36.2)	26 (11.4)	21 (9.2)

Higher scores indicate higher frequency of self-care behavior. 1, Never, 2, Rarely, 3, Sometimes, 4, Often, 5, Always
IBD, inflammatory bowel disease; SD, standard deviation

In contrast, the lowest mean scores were recorded for "Seek professional counseling or join support groups" (2.15±1.23) and "Ask for assistance from others" (2.38±1.06), indicating that supportive behaviors involving external resources were rarely practiced.

Turning to the self-care monitoring scale, the most frequently reported behaviors concerned the monitoring of patients' health status, with high scores for "Observe changes in your relative's physical condition" (4.21±0.83) and "Recognize early signs of illness worsening" (3.98±0.94). Conversely, behaviors related to caregivers' own wellbeing received the lowest ratings, specifically "Check your own emotional reactions" (2.46±1.09) and "Monitor your own level of fatigue" (2.68±1.02), suggesting limited attention to these specific self-monitoring behaviors.

As for the self-care management scale, the highest scores were obtained for "Take appropriate action if your relative's symptoms worsen" (4.12±0.88) and "Adjust daily routines according to your relative's health needs" (3.85±0.91), reflecting frequent efforts to manage the patient's clinical needs. On the other hand, the lowest scores were reported for "Seek immediate professional advice in case of uncertainty" (2.33±1.14) and "Use stress management techniques for yourself" (2.41±1.08), pointing to difficulties in taking advantage of external professional support and in implementing strategies for personal stress regulation.

In terms of response frequencies, adequate behavior (responses "often/always") ranged widely from 12.2% to 98.7% across items. The highest adequacy was observed for "Maintain daily personal hygiene" (98.7%) and "Eat all essential meals" (87.8%), while the lowest was for "Seek professional counseling or join support groups" (18.3%) and "Ask for assistance from others" (12.2%).

Notably, no statistically significant differences emerged between caregivers of patients with CD and UC.

Predictors of self-care behaviors

Among the 11 self-care behaviors, significant associations emerged for 4 items after Bonferroni correction, when modeling the likelihood of inadequate behavior (i.e., reporting scores from 1-3). Caregivers who were not married or partnered were significantly more likely to report inadequate engagement in physical activities compared to those who were married or partnered (OR 2.38, 95%CI 1.32-4.17; P=0.004, pBonf=0.044). Higher anxiety scores were associated with a greater likelihood of reporting inadequate attention to signs of discomfort (OR 1.32 per point, 95%CI 1.11-1.56; P=0.001, pBonf=0.011). In contrast, higher caregiver burden scores were linked to a higher probability of adequate use of techniques to enhance emotional wellbeing (OR 0.97 per point, 95%CI 0.95-0.99; P=0.004, pBonf=0.044), suggesting a protective role. Similarly, higher depression scores were associated with a higher likelihood of adequate help-seeking behaviors (OR 0.80 per point, 95%CI 0.68-0.93; P=0.004, pBonf=0.044) (Table 3).

Table 3 Significant predictors of inadequate caregiver self-care behaviors (11 binary logistic regression models, Bonferroni-corrected $\alpha = 0.05/11$)

Item	Significant predictors (direction, OR [95%CI], P, pBonf)
Self-care maintenance	
2. Do physical activities	Not married/partnered ↑ (2.38 [1.32–4.17]; *P*=0.004; pBonf=0.044)
Self-care monitoring	
13. Monitor your weight	None
16. Pay attention to signs of being overwhelmed	None
17. Pay attention to signs of fatigue	None
18. Pay attention to signs of discomfort	Anxiety ↑ (1.32 [1.11–1.56]; *P*=0.001; pBonf=0.011)
Self-care management	
19. Change caregiving efforts based on physical status	None
21. Increase regular sports activities	None
22. Adopt techniques to enhance your emotional wellbeing	Caregiver burden ↓ (0.97 [0.95–0.99]; *P*=0.004; pBonf=0.044)
25. Seek professional counseling/support group	None
26. Ask for assistance from others	Depression ↓ (0.80 [0.68–0.93]; *P*=0.004; pBonf=0.044)
27. Accept help from others	None

Odds ratios (OR) for continuous variables are per 1-point increase (e.g. caregiver burden, depression, and anxiety scores). Arrows denote direction of effect (↑ OR>1; ↓ OR <1). Reference categories: Relationship=Married/partnered vs. not. P-values were Bonferroni-corrected (pBonf) across the 11 primary outcomes ($\alpha\_corr=0.05/11=0.0045$). We multiplied each raw P by 11; if the result was still <0.05, the effect was considered significant. Rows marked "None" indicate that no predictor remained significant after this correction

CI, confidence interval

Discussion

The aim of this study was to identify patterns of adequate and inadequate self-care behaviors and to examine the sociodemographic, relational, and psychological factors associated with inadequate self-care among informal caregivers of patients with IBD. To our knowledge, it is the first investigation to systematically explore caregiver self-care in this context. Unlike prior research that has focused almost exclusively on caregiver burden or psychological distress, our work highlights an overlooked but crucial dimension: how caregivers sustain their own health in the face of unpredictable, stigmatizing and demanding illness trajectories. By shifting the focus from burden alone to proactive self-care, this study lays the groundwork for interventions that could transform not only caregiver resilience, but also patient outcomes.

Caregivers showed high engagement in basic self-care behaviors, such as maintaining daily hygiene, eating essential meals and avoiding smoking. These habits are probably sustained by routine and less influenced by emotional overload. More complex actions, such as seeking professional counselling, asking for assistance, or adjusting caregiving efforts based on personal health, were less common. Such behaviors require emotional openness, resource access and recognition of one's own needs, which many caregivers lack, partly as a result of the stigma and the crisis-driven nature of IBD care [14,44].

Several domains related to emotional regulation, help-seeking, and adaptive adjustment were notably suboptimal. Low engagement in counseling or support groups may reflect barriers related to self-reflection, perceived legitimacy of needs, or lack of access to support [24]. Our findings align with prior research showing that caregiving in the IBD context imposes substantial emotional burden and unpredictability for both patients and families [6,17].

Moreover, caregivers, like patients, often cope with anticipatory anxiety, chronic uncertainty and stigma, which hinder emotional adjustment and help-seeking behaviors [45,46]. Despite evidence that peer support or facilitated groups can offer meaningful relief, such resources remain underutilized by IBD caregivers [47,48]. This pattern is consistent with findings from oncology and dementia caregiving, where similar barriers, including stigma, lack of time and perceived unworthiness of support, limit participation in otherwise beneficial interventions [49-51]. This convergence underscores the need to normalize help-seeking and integrate emotionally supportive, caregiver-centered interventions into standard IBD care.

The tendency not to adjust caregiving according to personal health may reflect limited self-boundary awareness or guilt in reducing care intensity, patterns also reported in other fluctuating and stigmatizing conditions [16,52]. Isolation, both social and institutional, could also explain the low help-seeking scores [53].

The pattern of high engagement in routine self-care and low participation in psychologically demanding activities mirrors findings in caregivers of patients with heart failure or dementia [54]. In our analysis, the presence of a partner emerged as a protective factor, possibly by providing practical support, emotional buffering and division of responsibilities. Unpartnered caregivers may lack both logistical help and motivational reinforcement for health-promoting behaviors such as exercise [55,56].

Higher anxiety was linked to neglect of bodily discomfort, in line with models suggesting that chronic anxiety can reduce interoceptive awareness [57,58]. Caregiver burden was associated with a lower likelihood of inadequate adoption of emotional wellbeing strategies, such as mindfulness or relaxation [59,60]. In IBD, intimate and unpredictable care tasks, such as managing perianal complications, may further undermine resilience [15].

Higher depression scores were associated with a lower likelihood of inadequate help-seeking behavior. All regression models were interpreted with inadequate self-care behavior as the outcome variable; therefore, ORs below 1 indicate a lower probability of inadequate self-care behavior [61]. Stigma surrounding specific care tasks may exacerbate isolation. Because untreated caregiver depression can compromise patient adherence, continuity of care and overall outcomes, integrating mental health support into IBD services should be considered a clinical priority [62].

No significant predictors emerged for other self-care behaviors, suggesting that unmeasured systemic factors, such as access to safe exercise facilities, cultural attitudes toward self-care, and availability of respite care, may also play a role. Overall, while basic self-care behaviors appear resilient, emotionally and socially demanding domains remain fragile. These findings point to the need for structured, multidimensional interventions aimed at strengthening emotional wellbeing, promoting help-seeking, and enhancing adaptive coping strategies—ultimately benefiting both caregiver and patient outcomes.

This study presents several limitations that should be acknowledged. First, its cross-sectional design precludes any causal inference regarding the relationship between the examined predictors and self-care behaviors. Longitudinal studies are needed to clarify the directionality and temporal dynamics of these associations. Second, certain systemic or environmental factors, such as access to safe exercise spaces, cultural norms regarding self-care, or availability of respite services, were not captured and may influence engagement in more complex self-care behaviors. Third, the sample may not be fully representative of all IBD caregiver populations. In addition, given the survey-based, cross-sectional design, a potential risk of nonresponse bias cannot be entirely ruled out, as information on non-responders was not available. Although the multicenter and geographically diverse recruitment strategy enhanced sample heterogeneity, the study was not designed to achieve statistical representativeness at the population level. In particular, findings may not generalize to caregivers of older patients, those with severe or rapidly progressive disease, or individuals with limited caregiving experience or lower health literacy. Future research should consider these subgroups to improve the applicability of interventions. Although key sociodemographic, relational, and psychological variables were selected *a priori* to reduce confounding, residual confounding due to unmeasured factors (including specific caregiving roles) cannot be excluded.

An item-level analytical approach was chosen to capture the multidimensional nature of self-care and to identify specific predictors of inadequate behaviors. While this limited comparability with studies that use total scores, it aligned with our aim to explore behavioral vulnerabilities rather than to quantify overall self-care. Finally, all data were collected through self-report questionnaires, which may be subject to social desirability or recall biases, particularly when addressing emotionally sensitive domains such as psychological distress or help-seeking behaviors.

Future research should build upon these findings by adopting longitudinal or dyadic study designs to explore the causal and reciprocal pathways between psychological burden, caregiver identity and specific self-care practices. Mixed-method studies, integrating qualitative interviews or ethnographic observations, could provide richer contextual insights into the emotional, relational and environmental barriers that limit caregiver engagement in emotional regulation, help-seeking or adaptive caregiving behaviors.

From an implementation perspective, future intervention trials should explore the efficacy of psychoeducational, coaching, and peer-support programs aimed at enhancing caregiver self-efficacy and promoting engagement in both physical and psychological self-care domains. Tailored strategies that consider caregiver marital status, mental health vulnerabilities and disease unpredictability may prove particularly impactful.

In conclusion, this study is the first to systematically examine self-care behaviors among informal caregivers of IBD patients. While caregivers showed strong adherence to basic maintenance practices, significant gaps emerged in emotional and support-seeking behaviors, associated with psychological distress and relational factors. Interventions should not only promote physical wellbeing but also strengthen emotional resilience, facilitate help-seeking, and acknowledge the relational context of caregiving. Further attention should be given to caregivers without partner support, who may be at greater risk for behavioral self-care deficits.

Summary Box

What is already known:

- Informal caregivers of patients with inflammatory bowel disease (IBD) experience substantial burden and psychological distress
- Previous research has focused mainly on caregiver burden, with limited attention to caregiver self-care behaviors
- Evidence on the specific domains of self-care most affected in IBD caregivers is scarce

What the new findings are:

- Routine self-care behaviors among IBD caregivers are generally well maintained, whereas emotional and support-seeking behaviors are frequently inadequate
- Psychological factors (anxiety, depression, caregiver burden) and relational status are associated with specific patterns of inadequate self-care
- Item-level analysis identifies distinct self-care domains that may benefit from targeted caregiver-focused interventions

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