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Original article

HEALTH-RELATED QUALITY OF LIFE IN PATIENTS WITH INFLAMMATORY BOWEL DISEASE: A MIXED METHODS STUDY

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Abstract

Introduction: Inflammatory bowel disease (IBD) is a chronic disease that significantly affects health-related quality of life (HRQoL). This mixed-methods pilot study aimed to describe HRQoL in patients with IBD and preliminarily assess the validity and reliability of the Argentine Spanish version of the Inflammatory Bowel Disease Questionnaire-32 (IBDQ-32). Secondary objectives were to explore patients' subjective involvement with the disease and differences in HRQoL by sex, IBD type, and disease activity.

Materials and methods: An observational, descriptive, cross-sectional, mixed-methods pilot study was conducted at a University Hospital in Buenos Aires. Non-probability purposive sampling with consecutive recruitment was used. The Argentine Spanish version of the IBDQ-32 was used to assess its psychometric properties and HRQoL. Semi-structured interviews explored patients' subjective involvement with the disease.

Results: Seventy-three patients with IBD were included, 78.1% with ulcerative colitis (UC) and 21.9% with Crohn's disease (CD). The Argentine Spanish version of the IBDQ-32 demonstrated preliminary evidence of validity and reliability. High HRQoL was reported by 86.3% of patients, with significant differences between active and inactive disease ($p<0.0001$); women with active UC had the lowest scores. Among the main qualitative findings, frustration was identified in 76.7% of patients and irritability in 60.3%, both related to stress.

Conclusion: Although 86.3% of patients reported high HRQoL, elevated stress levels were identified. Women with active UC reported lower HRQoL than men and patients with CD. These findings support an interdisciplinary approach incorporating psychogastroenterology, particularly in patients with active disease and high stress.

Key words: inflammatory bowel diseases, ulcerative colitis, Crohn's disease, quality of life, psychological well-being

Resumen

Calidad de vida relacionada con la salud en pacientes con enfermedad inflamatoria intestinal: un estudio de métodos mixtos

Introducción: La enfermedad inflamatoria intestinal (EII) afecta significativamente la calidad de vida. El objetivo fue describir la calidad de vida relacionada con la salud (CVRS) en pacientes con EII y evaluar preliminarmente la validez y confiabilidad de la versión en español argentino del IBDQ-32 (Inflammatory Bowel Disease Questionnaire-32). Como objetivos secundarios, se exploraron la implicación subjetiva y las diferencias

en la CVRS según sexo, tipo de EII y actividad de la enfermedad.

Materiales y métodos: Estudio piloto, observacional, descriptivo, transversal y de métodos mixtos realizado en un hospital universitario de Buenos Aires. Se utilizó un muestreo no probabilístico intencional con reclutamiento consecutivo. Se empleó el IBDQ-32 versión español argentino para evaluar sus propiedades psicométricas y la CVRS. Se realizaron entrevistas semiestructuradas para explorar la implicación subjetiva de los pacientes.

Resultados: Se incluyeron 73 pacientes (78.1% colitis ulcerosa [CU] y 21.9% enfermedad de Crohn [EC]). El IBDQ-32 mostró evidencia preliminar de validez y confiabilidad. El 86.3% refirió alta CVRS, con diferencias significativas entre enfermedad activa e inactiva ($p < 0.0001$); las mujeres con CU activa presentaron los puntajes más bajos. En la fase cualitativa, se identificó frustración en el 76.7% e irritabilidad en el 60.3%, asociadas al estrés.

Conclusión: La mayoría de los pacientes reportó alta CVRS, pero se observaron altos niveles de estrés. Las mujeres con CU activa mostraron peor CVRS que los hombres y pacientes con EC. Estos hallazgos respaldan un abordaje interdisciplinario que incluya psicogastroenterología, particularmente en pacientes con enfermedad activa y elevado estrés.

Palabras clave: enfermedades inflamatorias intestinales, colitis ulcerosa, enfermedad de Crohn, calidad de vida, bienestar psicológico

KEY POINTS

Current knowledge

- Inflammatory bowel disease (IBD) significantly affects patients' quality of life, with disease activity and psychological factors playing key roles.

Article's contribution to current knowledge

- This study uses a mixed-methods approach, emphasizing the qualitative aspect to deeply explore the subjective impact of IBD, especially how stress, particularly in women with active ulcerative colitis, affects their quality of life. These findings highlight the importance of an interdisciplinary approach to the management of patients with active disease, with particular attention to psychological and psychosocial factors within the field of psycho-gastroenterology.

Inflammatory bowel disease (IBD) is a chronic, progressive disease characterized by periods of remission between episodes of inflammatory activity[1]. IBD is classified into two main types: Crohn's disease (CD) and ulcerative colitis (UC), both of which have a multifactorial origin and exhibit significant variability in their clinical course, influenced by genetic, environmental, and immunological factors[2]. Over the past decades, an increase in the incidence and prevalence of IBD has been observed in both developed and developing countries. Although these diseases most commonly manifest between the ages of 15 and 30 and between 60 and 80, they can develop at any stage of life[3].

Historically, IBD has been considered a psychosomatic disorder[4]. Although psychological factors have not been established as causal agents of CD or UC, evidence suggests an association between psychosocial stress, psychopathological aspects, and IBD, as well as their impact on treatment response[5]. IBD significantly affects psychological well-being and health-related quality of life (HRQoL), which should be considered an integral part of clinical care, as recommended by the European Crohn's and Colitis Organisation (ECCO)[6].

Psychological well-being is defined as the development of personal capabilities and growth, where an individual demonstrates indicators of positive functioning[7]. Health-related quality of life (HRQoL), on the other hand, refers to the level of well-being derived from a person's evaluation of various domains of their life, considering the impact of their health status, making it inherently subjective[8].

The primary objectives of this study were to describe HRQoL in patients with IBD using a mixed-methods approach (quantitative and qualitative), and to perform a preliminary assessment of validity and reliability of the Spanish Argentinian version of IBDQ-32 (licensed from McMaster Industry). The secondary objectives were to explore subjective patient involvement with the disease through semi-structured interviews and to analyze differences in quality of life according to patient subgroups defined by sex, IBD type, and disease activity level.

The IBDQ-32 has been translated, adapted, and validated in Spanish-speaking populations, including Spain and Mexico, providing method-

ological precedents for its use in patients with IBD[9,10]. However, its psychometric properties have not been evaluated in an Argentine population.

Materials and methods

Study design

This was an observational, descriptive, and cross-sectional study with a mixed quantitative and qualitative approach, conducted between March 2019 and February 2020. A non-probability, purposive sampling method was used. A total of 73 patients were included, all of whom were treated at the Inflammatory Bowel Disease Unit of the Gastroenterology Service at a University Hospital in Buenos Aires. Patients with IBD who attended the outpatient clinic of the IBD Unit were consecutively invited to participate following their consultation with the gastroenterologist. All patients who met the eligibility criteria and voluntarily agreed to participate were included during the study period. Recruitment was prematurely halted due to the onset of the COVID-19 pandemic. The purpose of the study was explained to all participants, and written informed consent was obtained from all participants (#880). The study was approved by the Ethics Committee of the British Hospital in Buenos Aires, Argentina.

Instruments and procedures

Following recruitment, participants were referred for a psychological consultation, where the IBDQ-32 questionnaire and the semi-structured interview were administered. Quality of life was assessed using the Spanish Argentinian version of the IBDQ-32 (licensed from McMaster Industry). The questionnaire consists of 32 items distributed across four dimensions: intestinal symptoms, systemic symptoms, emotional function, and social function. Each item is structured using a 7-point Likert scale, with total scores ranging from 32 to 224, where higher scores indicate better perceived quality of life. The self-administered questionnaire takes approximately 15-30 minutes to complete.

Regarding quality-of-life scoring, and in alignment with prior analyses by the developers of the IBDQ-32, low quality of life was defined as a total score between 32 and 95, moderate quality of life between 96 and 159, and high quality of life between 160 and 224[11]. Initially, we performed a preliminary assessment of the validity and reliability of the IBDQ-32 in Argentine patients with IBD. Since the questionnaire had not yet been validated in Argentina, this pilot study provided preliminary evidence regarding its applicability, internal consistency, and structure.

Subsequently, a semi-structured interview was conducted to complement and expand upon the data obtained through the IBDQ-32. Four additional questions from the Psychological Well-being Scale for Adults (BIEPS-A scale) on psychological well-being were included[12]. This qualitative data provided a deeper understanding of patients' perspectives and their subjective experiences with the disease (Supplementary material).

Population

The study included patients aged 16 years or older with a confirmed diagnosis of CD or UC who were treated at the hospital's Gastroenterology Service. IBD diagnosis was based on compatible clinical, endoscopic, histological, and imaging criteria, as documented in the medical record by the treating gastroenterologist. Patients without a confirmed diagnosis of CD or UC were excluded. Disease activity status (active/inactive) was determined by the treating gastroenterologist based on the Mayo score for UC and the Harvey–Bradshaw Index for CD, as documented in the medical record. Following recruitment, participants underwent a psychological consultation, where the IBDQ-32 questionnaire and the semi-structured interview were administered (Table 1).

Data analysis

Descriptive and statistical analyses were conducted using IBM SPSS Statistics 24.0 and ATLAS.ti 8. Qualitative variables were presented as frequencies and percentages, while continuous variables were reported as means, standard deviations and 95% confidence intervals (95% CI). Comparisons between groups were performed using the chi-square test for qualitative variables and t-tests or ANOVA for continuous variables, depending on whether there were two or more groups. Tukey's multiple comparisons test was performed. Graphs were generated using GraphPad Prism 8.01. For the primary comparison, effect size (Cohen's d) and post-hoc power were also calculated.

Qualitative data analysis

Qualitative data from the semi-structured interviews were analyzed using the constant comparative method within a Grounded Theory approach, following the principles described by Strauss and Corbin, with ATLAS.ti 8 software, from a post-positivist epistemological perspective. All interviews were thoroughly reviewed prior to coding to identify recurring concepts and patterns across participants' responses. Codes were generated in-

Table 1 | Demographic and clinical characteristics of patients

n	UC 57	CD 16	p
Women, n (%)	33 (57.9)	6 (37.5)	0.24
Age (years)	42.3 ± 14.8	47 ± 15.5	0.27
Disease activity, n (%)	20 (35.1)	6 (37.5)	0.85
IBDQ-32 total score	175.1 ± 29.1	173.1 ± 32.7	0.8
Low QoL (32-95)	0 (0%)	1 (6.2%)	0.23
Moderate QoL (96-159)	4 (7%)	5 (31.2%)	0.02
High QoL (160-224)	53 (93%)	10 (62.6%)	0.006

IBDQ: Inflammatory Bowel Disease Questionnaire, QoL: Quality of Life, UC: ulcerative colitis, CD: Crohn's disease

ductively and continuously compared across interviews, with related codes subsequently grouped into broader categories. These categories were organized within three main domains: emotional function and social function, consistent with the corresponding IBDQ-32 dimensions, and psychological well-being, an additional domain incorporated by the authors and informed by four items from the BIEPS-A scale. Code frequency (grounding) was used descriptively to identify the most prevalent codes and to examine patterns across patient subgroups according to sex, IBD type, and disease activity. Qualitative findings were interpreted alongside the quantitative results to provide a more comprehensive understanding of patients' subjective experiences of living with IBD. To further integrate the qualitative and quantitative components, findings from the semi-structured interviews were examined alongside the corresponding IBDQ-32 results. A joint display was used to identify areas of convergence and complementarity between the two data sources, particularly with regard to disease activity, quality of life, emotional function, and patient subgroups (Table 2).

Ethical considerations

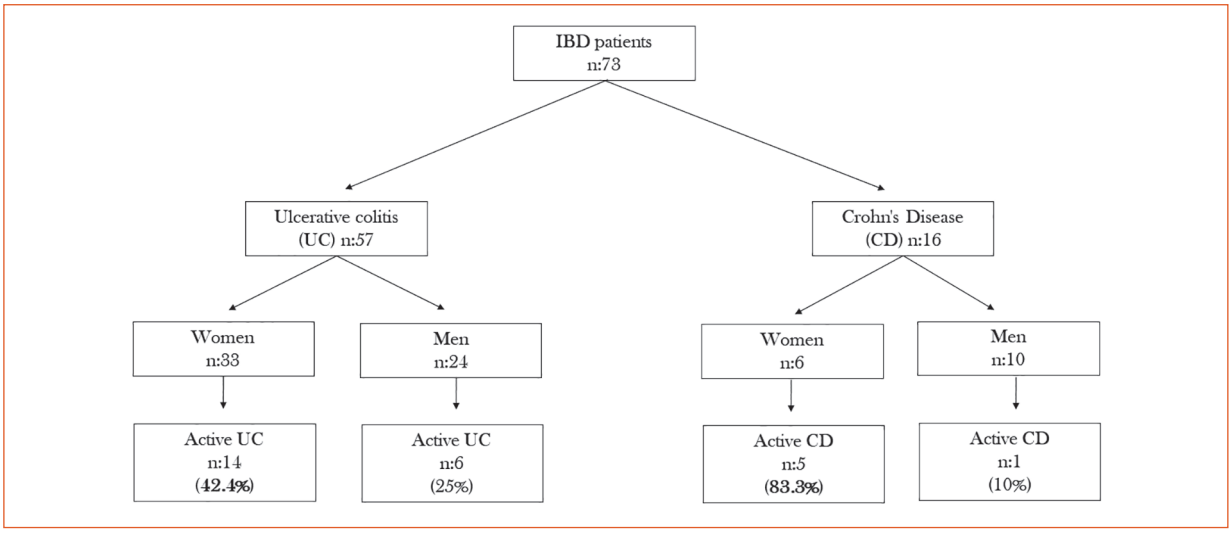
All patients provided written informed consent.

Results

Population description: A total of 73 patients with IBD participated in this study, of whom 57 (78.1%) had UC and 16 (21.9%) had CD. A higher proportion of disease activity was observed among female patients in both groups (Fig. 1). Patient age ranged from 18 to 72 years, with a mean age of 43.3 ± 15.02 years. The demographic characteristics of patients are detailed in (Table 1).

Application of the Argentine Spanish version of the IBDQ-32: Item discrimination analysis (contrasting the first and third quartiles using Student's t-test) showed good discriminative power ($p<0.05$) for 30 of the 32 items. Two items—item 18 (weight-related concerns) and item 32 (satisfaction with personal life)—did not reach statistical significance ($p=0.102$ and $p=0.215$, respectively). The psychometric properties of the Argentine Spanish version of the IBDQ-32 were then analyzed. Internal consistency reliability was excellent, with a Cronbach's alpha coefficient of 0.94 (95% CI: 0.915-0.957) for the total scale, 0.86 (95% CI: 0.804-0.902) for the digestive symptom's subscale, 0.58 (95% CI: 0.385-0.705) for the systemic symptoms subscale, 0.90 (95% CI: 0.806-0.931) for the emotional subscale, and 0.87 (95% CI: 0.819-0.913) for the social subscale. Notably, the social subscale, despite having fewer items, exhibited higher internal consistency. Before evaluating the scale's internal structure, sample adequacy was assessed using the Kaiser-Meyer-Olkin (KMO) index (0.836) and Bartlett's test of sphericity, ($\chi^2 = 1542.116$, $df = 496$, $p < 0.001$), confirming the suitability of factor analysis. The internal structure of the scale was found to align with the original dimensions reported in prior studies, with a total explained variance of 58.3%, indicating an acceptable level. Based on these findings, the Argentine Spanish version of the IBDQ-32 provided preliminary evidence of validity and reliability in this sample.

Figure 1 | Flow Diagram of the studied patients



Application of the Argentine Spanish version of the IBDQ-32

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Quality of life: According to the IBDQ-32, 86.3% (n=63) of the total sample reported high quality of life, 12.3% (n=9) reported moderate quality of life, and only 1 patient (1.4%) reported low quality of life (Table 1). A significant reduction in total quality-of-life scores was observed in patients with active UC and CD compared to those in remission (148.0 ± 34.6; 95% CI: 127.9–166.9 vs. 185.5 ± 19.0; 95% CI: 179.2–190.9; $p < 0.0001$). The effect size for this comparison was large (Cohen's $d = 1.54$), with a post-hoc power exceeding 99%.

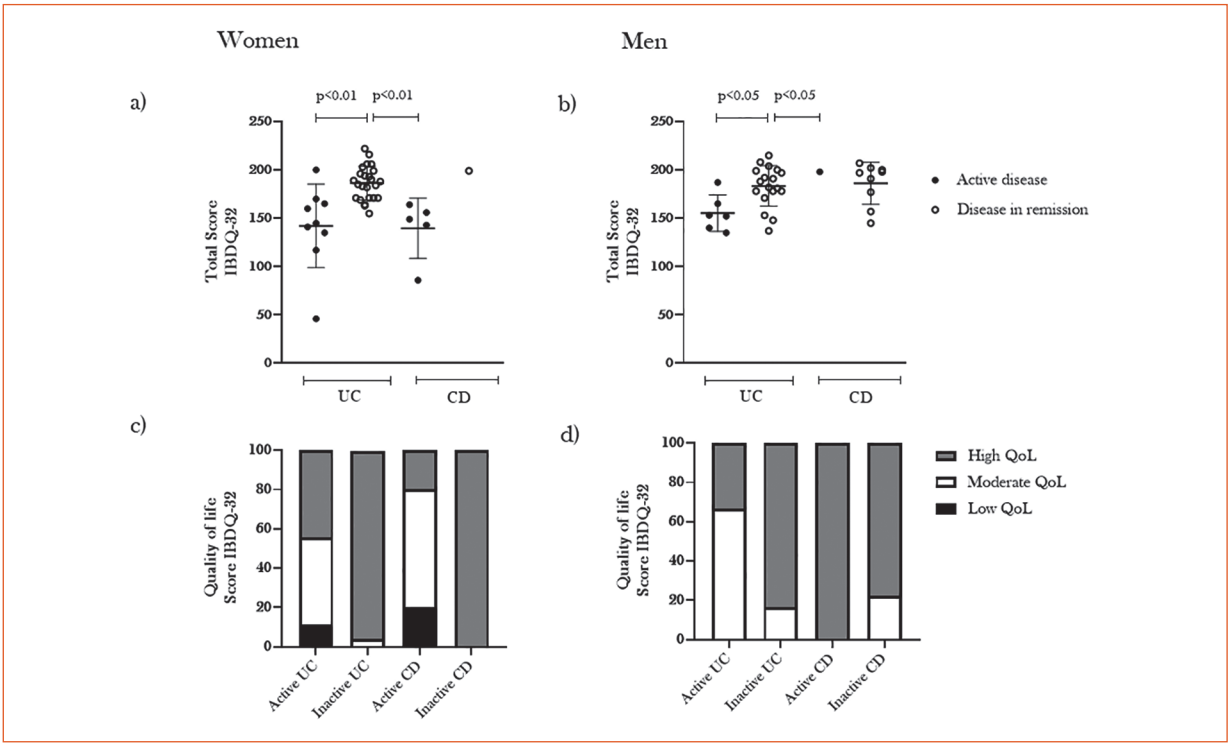
These results were confirmed when stratified by sex. A decrease in total scores was observed in women with active UC and CD compared to those with inactive disease (142.1 ± 43.16, 95% CI: 108.9–175.3 and 139.6 ± 30.97, 95% CI: 101.1–178.1 vs. 186.3 ± 17.3, 95% CI: 179.0–193.6 and 199.0 ± 0, respectively; $p = 0.0002$) (Fig. 2a). Similarly, among men, the results were 155.3 ± 18.7 (95% CI: 135.6–175.0) and 198.0 ± 0 vs. 183.3 ± 20.9 (95% CI: 172.9–193.8) and 186.0 ± 21.7 (95% CI: 169.3–202.7), respectively ($p = 0.028$) (Fig. 2b). When patients were grouped according to IBDQ-32 score strata, a statistically significant reduction in high quality of life was observed among women with active UC compared to those with-

out disease activity (44.4% vs. 95.4%; $p = 0.0028$) (Fig. 2c). Similar, though non-significant, effects were observed in patients with CD (Fig. 2d).

Qualitative findings

Emotional function: As observed in Fig. 3a, satisfaction with personal life prevailed in 80.8% of patients, with clinical improvement cited as a relevant contributing factor. Conversely, dissatisfaction with personal life was linked to work-related stress, relationship issues, anxiety about disease relapse, and fertility problems. In this study, more than half of the patients reported experiencing frustration, impatience, and restlessness (76.7%). Frustration was frequently associated with stress (e.g., *"I attribute it mostly to my work situation"; "I think, in part, it's personal matters"*). A state of relaxation and the absence of tension were predominant in 64.4% of patients, mainly attributed to enjoying family life, moments of rest, psychological treatment, yoga, and solitude. In contrast, lack of relaxation and the presence of tension were primarily associated with work-related stress, disease symptoms, and academic concerns. Irritability was present in 60.3% of patients, linked to work-related stress, disease symptoms, and feelings of anger (e.g., *"I think it's because of the illness—since this started happening to me, having to be in this situation again really makes me angry"; "If I notice my stomach bothering me or something like that, it irritates me"*). Feeling depressed or discouraged was reported by 53.4% of patients, with stress being a common contributing factor, whereas the ab-

Figure 2 | Perception of Quality of Life (IBDQ-32) grouped by sex



a) and b) Total score of the Perception of Quality of Life (IBDQ-32) grouped by type of inflammatory bowel disease (UC or CD) and presence or absence of disease activity in women (a) and men (b).
c) and d) Percentage of patients in the different ranges of Perception of Quality of Life (IBDQ-32) categorized as high, moderate, and low, grouped by type of inflammatory bowel disease (UC or CD) and presence or absence of disease activity in women (c) and men (d)
IBDQ-32. Inflammatory Bowel Disease Questionnaire; UC: ulcerative colitis; CD: Crohn's disease

sence of depressive symptoms was associated with positive thinking, physical activity, and psychological treatment. Anxiety and concern about the disease were present in 57.5% of patients. The main sources of worry included fear of relapse, concerns about developing cancer, and distress related to a recent diagnosis. During interviews, 41.1% of patients reported feeling deeply distressed to the point of tears, citing disease symptoms, relationship issues, and work-related stress as primary reasons. In our study, 37% of patients experienced anger, primarily related to disease symptoms and difficulty accepting the condition (e.g., *"Why is this happening to me?"; "Having to always be mindful of taking medication, or being careful with certain foods"*). Furthermore, 35.6% of patients reported feeling misunderstood by others, including family, partners, workplace colleagues, and society in general, often due to a lack of awareness about the disease. Additionally, 34.2% of patients expressed fear of not finding a restroom nearby, with concerns primarily centered on anticipation and hygiene (e.g., *"Before leaving my house, I go back and forth, back and forth, checking whether I need to use the bathroom, so it doesn't happen to me on the street or somewhere else"*). This fear was observed even in those with a preserved quality of life. Moreover, 24.6% of patients reported feeling ashamed of their disease, citing symptoms, treatment, and the diagnosis label of "ulcerative colitis" as key factors (e.g., *"Everyone asks you about it, and it's embarrassing to say, 'I have an intestinal ulcer'"; "Yes, because sometimes you have flatulence"*). Regarding patients' fears, 23.3% reported concerns about undergoing surgery, whereas the absence of surgical anxiety was linked to confidence in various therapeutic options. In relation to sexual activity, 23.3% of patients reported limitations, citing reduced sexual activity due to disease, physical pain, discomfort, and shame.

Social function: In the social domain, 17.8% of patients reported limitations in engaging in physical activity, with fatigue and pain due to the disease cited as primary reasons. Additionally, 15.1% of patients postponed or canceled social commitments, citing fatigue and symptom anticipation, while another 15.1% avoided attending events where restroom access was uncertain (Fig. 3b).

Psychological Well-Being: Regarding psychological well-being, most patients did not report difficulties in future planning, managing daily responsibilities, expressing emotions, or receiving emotional support from their social environment. In patients who lacked emotional support from their social environment, we observed tendencies toward loneliness, relationship difficulties, introversion, and overadjustment to the disease (Fig. 3c).

Patients with active disease: A qualitative analysis of this subgroup (n=21), representing 28.8% of the total sample, was conducted using the same domains analyzed in the overall sample. Among patients with active disease, 17.8% (n=13) reported a perception of moderate to low quality of life. In our sample, this subgroup included 15.8% (n=9) with ulcerative colitis and 25% (n=4) with CD. Among patients with active disease and moderate to low quality of life, predominant emotional factors included frustration, impatience, restlessness, depression or discouragement, irritability, and anxiety about the disease. Concerns about surgery were linked to treatment burdens, relapses, and fear of cancer. Perceived lack of understanding from others was primarily attributed to family and work-related issues. Despite these findings, psychological well-being remained preserved even in patients who reported lower quality of life.

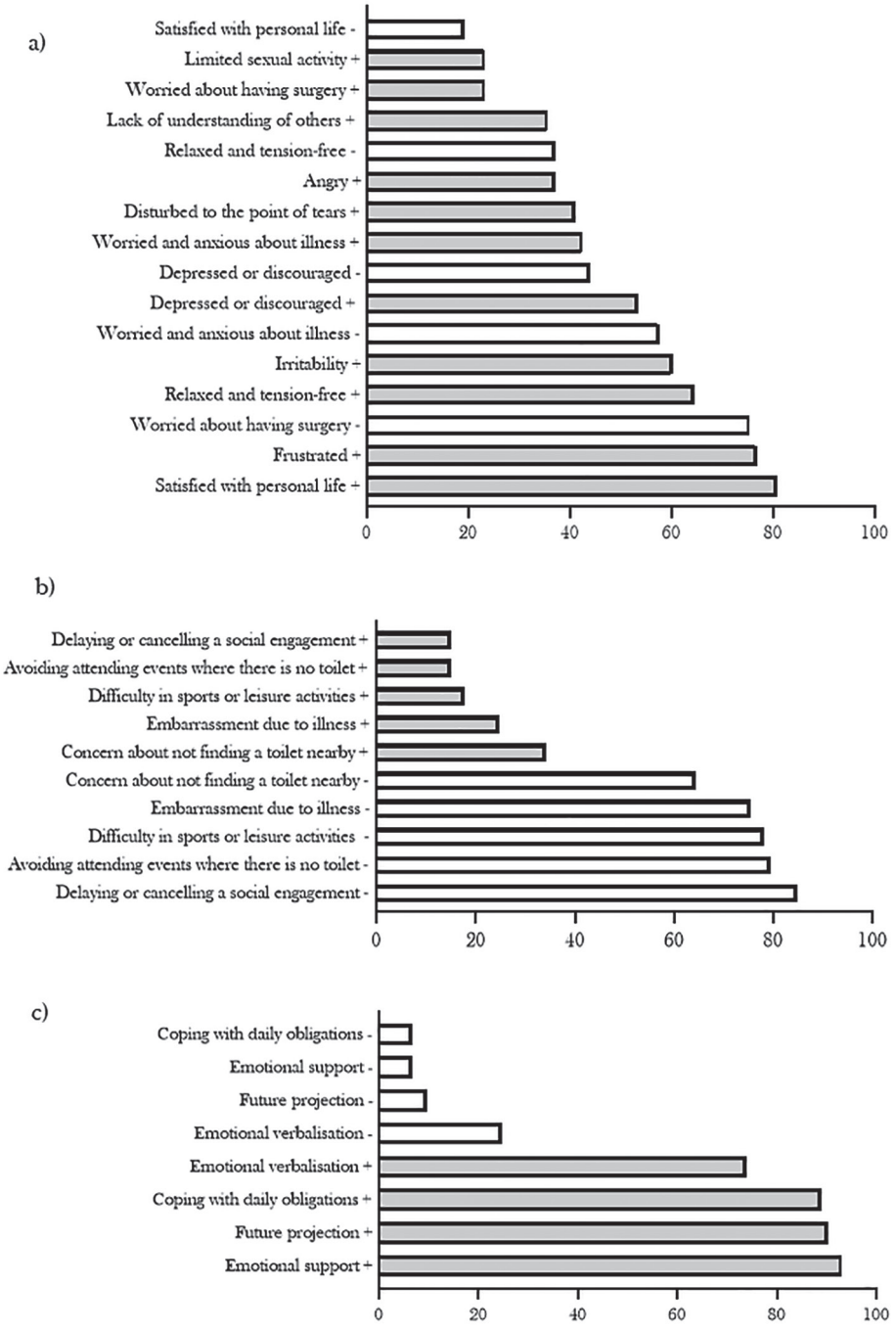
The quantitative and qualitative findings were considered together to identify areas of convergence and complementarity, providing a more comprehensive understanding of health-related quality of life and patients' subjective experiences with IBD. The main integrated findings are presented in Table 2.

Discussion

Patients with active UC and CD showed a significant reduction in total quality-of-life scores compared to those in remission. These findings align with a meta-analysis of over 2300 IBD patients, which demonstrated that active disease states were associated with greater declines in quality of life due to symptom exacerbation and its impact on daily activities and emotional well-being[13, 14].

In our sample, women with active UC reported lower perceived quality of life than men and

Figure 3 | Qualitative analysis of response frequencies.



a: Frequencies of emotional function. b: Frequencies of social function. c: Frequencies of psychological well-being. In gray, affirmative response frequencies are shown, and in white, negative response frequencies

patients with CD. These findings are in line with evidence suggesting sex-related differences in health-related quality of life among patients with IBD, although the available literature remains heterogeneous across disease subtypes and disease activity states[15]. Lungaro et al. similarly reported that women with IBD may experience greater psychological distress and poorer

Table 2 | Integration of quantitative and qualitative findings

Quantitative finding	Convergent qualitative finding	Integration
Total quality-of-life scores were significantly lower in active disease compared to inactive disease (p<0.0001)	Frustration (76.7%), irritability (60.3%), and anxiety/worry about the disease (57.5%) were predominantly linked to stress and symptom burden.	**Convergence** The qualitative findings provide contextual insight into the subjective experiences associated with the lower quality of life scores observed in patients with active disease.
Women with active UC showed lower total scores and a lower prevalence of high quality of life (44.4% vs. 95.4% in inactive disease; p=0.0028)	Among patients with active disease (n=21), predominant emotional themes included frustration, discouragement, irritability, and disease-related anxiety, with perceived lack of understanding linked to family and work.	**Convergence** Subjective distress is concentrated in the same subgroup that shows the greatest quantitative decline, providing complementary qualitative support for the quantitative finding.
86.3% of the total sample reported high quality of life	Satisfaction with personal life (80.8%); relaxation/absence of tension (64.4%); preserved psychological well-being (future planning, managing responsibilities, emotional expression).	**Convergence** The predominance of positive, adaptive qualitative categories mirrors the high overall quality of life scores, supporting the same conclusion from a different data source.
The IBDQ-32 includes a single item addressing anger (emotional domain)	Interviews revealed that 37% of patients experienced anger, linked to symptom burden and difficulty accepting the disease.	**Complementarity** The qualitative data does not simply confirm the quantitative item but expands and enriches it, revealing the underlying context and sources of a construct the questionnaire measures with limited granularity.

IBDQ-32 = Inflammatory Bowel Disease Questionnaire, 32 items; UC = ulcerative colitis
Integration of key IBDQ-32 findings with corresponding qualitative categories derived from semi-structured interviews

quality of life than men, although sex-related differences vary according to disease characteristics and clinical context[16].

Taken together, the quantitative and qualitative findings provide complementary perspectives on health-related quality of life in patients with IBD. Although most patients reported a preserved quality of life according to the IBDQ-32, the qualitative findings revealed a substantial emotional burden, particularly in relation to stress, frustration, irritability, and anxiety about the disease. These findings illustrate how qualitative exploration can provide additional context to the dimensions captured by the questionnaire. Stress, anxiety, and depression have been strongly linked to lower quality of life in patients with IBD[17]. In fact, perceived stress can worsen disease activity, contributing to flare-ups and indirectly affecting well-being[18,19]. In this context, interventions such as psychological therapy and yoga have shown evidence-based benefits in improving patients' quality of life[20, 21]. On another

note, while research on academic challenges in this population is still limited, studies have found that adolescents with IBD are more likely to face school-related difficulties than their healthy peers[22, 23]. This may be related to the emotional challenges of living with a chronic disease, reinforcing the importance of addressing mental health and stress management as part of a comprehensive approach to care.

Irritability was common among our patients, often arising in response to work-related stress, disease symptoms, and underlying anger. This interplay between irritability and anger stands out as an area that merits deeper investigation and targeted clinical intervention. Although the IBDQ-32 includes a single item on anger, our qualitative interviews revealed deeper insights into its underlying causes. Many patients reported experiencing anger, primarily linked to the burden of disease symptoms and challenges in accepting their condition.

Anxiety and concerns about the disease were common among patients, with major sources of worry including fear of relapse, concerns about developing cancer, and distress related to a recent diagnosis. These fears are clinically significant and should be addressed through a comprehensive care approach. In contrast, patients who reported little to no worry about their disease often cited disease acceptance and stabilization as key factors. Promoting disease acceptance could be an important therapeutic goal, potentially enhancing patient commitment to their health.

Many patients reported feeling misunderstood by family members, partners, colleagues, and society at large, often reflecting a general lack of awareness about the disease. Studies on social support, including those by Hanlin Fu et al., indicate that strong support networks can alleviate pain and stress, serve as protective factors against psychological disorders, and enhance self-regulation. Conversely, low perceived social support has been linked to poorer quality of life in patients with inflammatory bowel disease[24]. Given these insights, a deeper analysis of social support levels is crucial for these patients, along with an integrative approach that includes family involvement in treatment and group interventions where patients may find identification and support among peers.

A considerable proportion of patients reported feeling ashamed of their disease, attributing these emotions to symptom burden, treatment regimens, and the diagnostic label of "ulcerative colitis". This notable prevalence of shame mirrors findings by Almeida Trindade et al, who observed similarly elevated shame levels in IBD patients despite the underlying mechanisms remaining poorly understood[25]. Unraveling the origins of this shame —particularly its ties to symptoms, therapies, and diagnostic terminology— could guide the development of more effective psychological interventions for these individuals.

A notable proportion of patients reported limitations in sexual activity, attributing these challenges to disease, physical pain, discomfort, and feelings of shame. This underscores a novel association between shame and its impact on sexual well-being.

In the social domain, patients often reported limitations in engaging in physical activity, primarily due to disease-related fatigue and pain. Recent studies highlight the benefits of exercise for IBD patients—including counteracting specific disease effects, enhancing immune response, supporting psychological well-being, improving nutritional status and bone mineral density, and mitigating loss of muscle mass and strength[26]. Moreover, Wiestler et al. observed that patients in remission maintain higher levels of physical activity than those with active disease[27].

Regarding psychological well-being, the majority of patients did not experience difficulties with future planning, managing daily responsibilities, expressing emotions, or receiving emotional support from their social environment. Based on this, we conclude that psychological well-being is largely maintained in our patients, aligning with the overall perception of a high quality of life.

Our findings highlight the high prevalence of stress-related emotional themes among patients in this sample. While this study did not measure biological markers of stress, existing literature independent of our findings indicates that stress can influence intestinal inflammation, gut per-

meability, and microbiota composition[28, 29]. Evidence from psychoneuro-immunoendocrinology suggests that the effects of psychological stress on immune and inflammatory function depend on stress duration and intensity. Chronic and acute stress are associated with systemic immune and inflammatory dysfunction, which may be relevant to IBD pathogenesis[30]. Moreover, prior studies have demonstrated that individuals with persistently active symptoms experienced higher levels of stress than those whose symptoms remained inactive[31].

Therefore, the management of these patients requires a multidisciplinary team with individualized treatment plans. In line with existing recommendations to incorporate psychogastroenterology into the care of digestive disorders, our findings support this approach, considering the bio-psycho-social-spiritual aspects of each patient[32]. Historically, psychodynamic therapy, cognitive-behavioral therapy, acceptance and commitment therapy, stress management therapy, and mindfulness have been the primary psychological approaches in treating these diseases. Complementary interventions such as meditation, relaxation, yoga, physical activity, and spirituality have also shown efficacy in improving quality of life[21].

To our knowledge, this is the first pilot study assessing the validity and reliability of the IBDQ-32 in an Argentine population with IBD, and one of few studies examining health-related quality of life in this population in Argentina. Additionally, the mixed-methods design allowed for a more comprehensive understanding of patients' experiences than either approach alone: while the quantitative results indicated an overall preserved quality of life, the qualitative findings revealed a substantial emotional burden that the IBDQ-32 alone could not fully capture, underscoring the added value of qualitative exploration in this population.

This study has several limitations. First, it was conducted at a single institution, which may constrain the generalizability of the findings. Second, no a priori sample size calculation was performed, as this was a pilot study with non-probability purposive sampling; the sample size was small overall and particularly limited for the CD subgroup (n=16), which reduces statistical power for comparisons between UC and CD. Several subgroup analyses—stratified by sex, disease activity, and IBD type—should therefore be considered exploratory, with an increased risk of Type II error. Relatedly, the ratio of cases to items in the factor analysis (n=73 for 32 items, approximately 2.3 cases per item) was below the commonly recommended threshold of 5–10 cases per item, further supporting the preliminary, pilot nature of this psychometric evaluation. Third, recruitment was prematurely interrupted in February 2020 due to the onset of the COVID-19 pandemic, which may have further limited the total number of patients included. Fourth, although both instruments were administered during patients' scheduled consultations at the Inflammatory Bowel Disease Unit within the hospital's Gastroenterology Service, rather than through a separately sought psychological consultation, patients attending regular follow-up may not fully represent the broader IBD population.

Regarding future lines of research, we first consider the potential for a multicenter study, which could provide greater sample diversity and strengthen the generalizability of the findings. It would also be valuable to explore in greater depth several insightful aspects that emerged from this study, such as the impact on quality of life related to fertility issues, fear of infertility, the experience of motherhood, academic performance in young adults, and the high frequency of perceived anger and shame. Continued investigation of these variables could make a significant contribution to the understanding and treatment of quality of life in patients with inflammatory bowel disease.

In conclusion, the Argentine Spanish version of the IBDQ-32 demonstrated preliminary evidence of validity and reliability in our sample. Female patients with ulcerative colitis in an active disease state reported lower quality of life compared to patients with Crohn's disease and male patients. Although 86.3% of patients showed preserved quality of life, high levels of stress and frequent reports of anger and shame were identified, particularly among those with active disease.

It is worth further exploring the revealing aspects that emerged from this research, such

as the impact of the disease on quality of life in relation to fertility and motherhood issues, as well as its effect on academic performance in young adults. The findings of this mixed-methods study support the need for a comprehensive clinical management approach, incorporating psychogastroenterology as a specific framework for patients with active disease and elevated stress.

Conflict of interest: None to declare

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References

1. McDowell C, Farooq U, Haseeb M. Inflammatory bowel disease. [Updated 2023 Aug 4]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2025 Jan.
2. Le Berre C, Honap S, Peyrin-Biroulet L. Ulcerative colitis. *Lancet* 2023; 402: 571-84.
3. Friedman S, Blumberg RS. Enfermedad intestinal inflamatoria. In: Harrison T, Fauci AS, Kasper DL, Hauser SL, Longo DL, Loscalzo J, editores. *Principios de Medicina Interna,* 21ª ed. Ciudad de México: McGraw-Hill; 2022, p 2102-18.
4. Drossman DA, Creed FH, Olden KW, Svedlund J, Toner BB, Whitehead WE. Psychosocial aspects of the functional gastrointestinal disorders. *Gut* 1999; Suppl 2: II25-30.
5. Levenstein S. Psychosocial factors in peptic ulcer and inflammatory bowel disease. *J Consult Clin Psychol* 2002; 70: 739-50.
6. Van Assche G, Dignass A, Reinisch W, et al. The second European evidence-based Consensus on the diagnosis and management of Crohn's disease: Special situations. *J Crohns Colitis* 2010; 4: 63-101.
7. Díaz D, Rodríguez-Carvajal R, Blanco A, et al. Adaptación española de las escalas de bienestar psicológico de Ryff. *Psicothema* 2006; 18: 572-7.
8. Urzúa M. Calidad de vida relacionada con la salud: elementos conceptuales. *Rev Med Chile* 2010; 138: 358-65.
9. Masachs M, Casellas F, Malagelada JR. Traducción, adaptación y validación al español del cuestionario de calidad de vida de 32 ítems (IBDQ-32) de la enfermedad inflamatoria intestinal. *Rev Esp Enferm Dig* 2007; 99: 511-9.
10. Zavala-Solares MR, Salazar-Salas L, Yamamoto-Furusho JK. Validity and reliability of the health-related questionnaire IBDQ-32 in Mexican patients with inflammatory bowel disease. *Gastroenterol Hepatol* 2021; 44: 711-8.
11. Guyatt G, Mitchell A, Irvine EJ, et al. A new measure of health status for clinical trials in inflammatory bowel disease. *Gastroenterology* 1989; 96: 804-10.
12. Casullo M. Evaluación del bienestar psicológico en Iberoamérica. Buenos Aires: Ed. Paidós; 2002.
13. Knowles SR, Graff LA, Wilding H, et al. Quality of life in inflammatory bowel disease: A systematic review and meta-analyses—Part I. *Inflamm Bowel Dis* 2018; 24: 742-8.
14. Knowles S, Keefer L, Wilding H, et al. Quality of life in inflammatory bowel disease: A systematic review and meta-analyses—Part II. *Inflamm Bowel Dis* 2018; 24: 966-75.
15. Salem DA, El-Ijla R, AbuMusameh RR, et al. Sex-related differences in profiles and clinical outcomes of inflammatory bowel disease: a systematic review and meta-analysis. *BMC Gastroenterol* 2024; 24: 425.
16. Lungaro L, Costanzini A, Manza F, et al. Impact of female gender in inflammatory bowel diseases: a narrative review. *J Pers Med* 2023; 13: 165.
17. Iglesias-Rey M, Barreiro-de Acosta M, Caamaño-Isorna F, et al. Psychological factors are associated with changes in the health-related quality of life in inflammatory bowel disease. *Inflamm Bowel Dis* 2014; 20: 92-102.
18. Barello S, Guida E, Leone S, Previtali E, Graffigna G. Does patient engagement affect IBD patients' health-related quality of life? Findings from a cross-sectional study among people with inflammatory bowel diseases. *Health Qual Life Outcomes* 2021; 19: 77.
19. Bernstein CN, Singh S, Graff LA, Walker JR, Miller N, Cheang M. A prospective population-based study of triggers of symptomatic flares in IBD. *Am J Gastroenterol* 2010; 105: 1994-2002.

20. Paulides E, Boukema I, van der Woude CJ, de Boer NKH. The effect of psychotherapy on quality of life in IBD patients: A systematic review. *Inflamm Bowel Dis* 2021; 27: 711-24.
21. Torres J, Ellul P, Langhorst J, et al. European Crohn's and Colitis Organisation Topical Review on Complementary Medicine and Psychotherapy in Inflammatory Bowel Disease. *J Crohns Colitis* 2019; 13: 673-685e.
22. Mackner LM, Bickmeier RM, Crandall WV. Academic achievement, attendance, and school-related quality of life in pediatric inflammatory bowel disease. *J Dev Behav Pediatr* 2012; 33: 106-11.
23. Sachar Y, Gill JS, Chande N. Impact of inflammatory bowel disease on student experience in postsecondary education. *J Am Coll Health* 2024; 72: 203-9.
24. Fu H, Kaminga AC, Peng Y, et al. 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 Gastroenterol* 2020; 20: 11.
25. Trindade IA, Ferreira C, Pinto-Gouveia J. Shame and emotion regulation in inflammatory bowel disease: Effects on psychosocial functioning. *J Health Psychol* 2020; 25: 511-21.
26. Kim B, Chae J, Kim EH, et al. Physical activity and quality of life of patients with inflammatory bowel disease. *Medicine (Baltimore)* 2021; 100: e26290.
27. Wiestler M, Kockelmann F, Kück M, et al. Quality of life is associated with wearable-based physical activity in patients with inflammatory bowel disease: A prospective, observational study. *Clin Transl Gastroenterol* 2019; 10: e00094.
28. Bonaz BL, Bernstein CN. Brain-gut interactions in inflammatory bowel disease. *Gastroenterology* 2013; 144: 36-49.
29. Bailey MT, Dowd SE, Galley JD, Hufnagle AR, Allen RG, Lyte M. Exposure to a social stressor alters the structure of the intestinal microbiota: Implications for stressor-induced immunomodulation. *Brain Behav Immun* 2011; 25: 397-407.
30. Mawdsley JE, Rampton DS. Psychological stress in IBD: New insights into pathogenic and therapeutic implications. *Gut* 2005; 54: 1481-91.
31. Graff LA, Walker JR, Lix L, et al. The relationship of inflammatory bowel disease type and activity to psychological functioning and quality of life. *Clin Gastroenterol Hepatol* 2006; 4: 1491-501.
32. Keefer L, Palsson OS, Pandolfino JE. Best practice update: Incorporating psychogastroenterology into management of digestive disorders. *Gastroenterology* 2018; 154: 1249-57.

SUPPLEMENTARY MATERIAL
SEMI-STRUCTURED PSYCHOLOGICAL INTERVIEW

The purpose of this interview is to explore, from the subjective perspective of patients with IBD, the results of the IBDQ-32, expanding on the questionnaire items that cover the dimensions of "emotional function" and "social function." Additionally, new questions are introduced to further investigate psychological well-being, as well as emotional, social, and occupational areas.

Below are the questions from the IBDQ-32 'emotional function' dimension that were used:

3) How often during the last two weeks have you felt frustrated, impatient, or restless?
(Evaluates feelings of frustration).

7) How often during the last two weeks did you feel worried about the possibility of needing to have surgery because of your bowel problem?
(Evaluates illness-related fears and treatment adherence).

15) How often during the past two weeks have you felt depressed or discouraged?
(Evaluates dysphoric mood).

19) Many patients with bowel problems often have worries and anxieties related to their illness. These include worries about getting cancer, worries about never feeling any better, and worries about have a relapse. In general, how often during the last two weeks have you had felt worried or anxious?
(Evaluates anxiety and/or distress).

21) How often during the last two weeks have you felt relaxed and free of tension?
(Evaluates mood state).

25) How much of the time during the last two weeks have you felt tearful or upset?
(Evaluates heightened dysphoric mood).

27) How much of the time during the last two weeks have you felt angry as a result of your bowel problem?
(Evaluates feelings of anger).

28) To what extent has your bowel problem limited sexual activity during the last two weeks?
(Evaluates sexual functioning).

30) How much of the time during the last two weeks have you felt irritable?
(Evaluates mood state).

31) How often during the last two weeks have you felt lack of understanding from others?
(Evaluates interpersonal relationships and emotional support capacity).

32) How satisfied, happy, or pleased have you been with your personal life during the past two weeks?
(Evaluates emotional satisfaction).

Below are the questions from the IBDQ-32 'social function' dimension that were used:

8) How often during the last two weeks have you had to delay or cancel a social engagement because of your bowel problem?

11) How often during the last two weeks have you been troubled because of fear of not finding a wash-room?

12) How much difficulty have you had, as a result of your bowel problems, doing leisure or sports activities you would have liked to have done during the last two weeks?

16) How often during the last two weeks have you had to avoid attending events where there was no washroom close at hand?

23) How much of the time during the last two weeks have you felt embarrassed as a result of your bowelk problem?

Questions on Psychological Well-Being:

1) It is important for me to think about what I will do in the future. (Evaluates ability to project forward).

2) I can express what I think without major difficulties. (Evaluates emotional expression).

3) I have people I can rely on if I need help. (Evaluates emotional support from social context).

4) I manage my daily responsibilities without major problems. (Evaluates psychological functioning).

Questions on Emotional, Social, and Occupational Areas:

1) Marital status and household composition

2) Occupation

3) Social support network