Does patient engagement affect IBD patients' health-related quality of life? Findings from a cross-sectional study among people with inflammatory bowel diseases

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Abstract

Background: Patients diagnosed with inflammatory bowel disease (IBD) are required to deal with the unpredictability of this clinical condition, which is associated with poorer health-related quality of life (HRQoL) compared to other clinical conditions. Patient engagement is currently demonstrated to relate with chronic patients' HRQoL, but few studies have been conducted among this population.

Methods: A cross-sectional study was conducted among 1176 IBD patients. Data were collected on participants' HRQoL (SIBD-Q) and patient engagement (PHE-s®). Regression analysis was used to examine the effects of patient engagement on HRQoL.

Results: About the half of the sample (47%) reported a low patient engagement level. 30% of the sample reported a low level of HRQoL. Psycho-emotional functioning resulted to be the aspect of HRQoL most impacted in the 37% of the sample. The regression model showed that PHE-s® is significantly related to the SIBD-Q total score (B = .585; p < .001; R squared = .343) and to the subscales' scores—systemic symptoms (B = .572; p < .001; R squared = .327), bowel symptoms (B = .482; p < .001; R squared = .232), social (B = .485; p < .001; R squared = .234) and psycho-emotional (B = .607; p < .001; R squared = .369) functioning.

Conclusions: Patients who are engaged in their IBD care pathway are more likely to report higher level of HRQoL, thus offering clues to potential therapeutic approaches to ameliorating IBD patients' wellbeing. As this is a modifiable factor, screening for patient health engagement levels, coupled with appropriate interventions, could improve care, and ultimately improve HRQoL outcomes among IBD patients.

Keywords: Patient engagement, Health-related quality of life, Inflammatory bowel diseases, Healthcare, PHE-s®

Background

At the turn of the twenty-first century, Inflammatory Bowel Disease (IBD) has become a global disease with increased incidence in newly industrialised countries.

The global epidemiology of IBD has changed substantially over time, with a recent review demonstrating an increasing incidence of inflammatory bowel disease in developing nations and a stabilising incidence in developed nations [1][1][1]. The incidence rate of Crohn's disease (CD) in Italy is lower than those reported for other Mediterranean countries; in contrast, the Ulcerative Colitis (UC) incidence rate is within the range of those reported in European studies[4].
CD and UC are the two main conditions that collapse into IBD, that is an idiopathic disease of the gastrointestinal system that is characterized by chronic bowel inflammation [5]. They can affect any age group, have a significant impact on working age populations and lead to a considerable societal and economic burden. The goal of treatment for IBD is to diminish or eliminate disease activity and optimize health-related quality of life (HRQoL). Thus, healthcare services need to address any factors that might contribute to disease flares and diminished HRQoL [6, 7].

Patients diagnosed with IBD are required to deal with the uncertainty of the symptoms and the unpredictability of this clinical condition along their illness journey [6, 8]. Particularly, these factors can greatly inhibit their personal, social, employment, and recreational functioning, thus deeply impacting their HRQoL. For these reasons, beside medical and physical consequences, IBD can also have a significant negative impact on patients’ HRQoL.

Factors that appear to affect the HRQoL of IBD patients include the disease course (extent, severity, and pattern of symptoms’ relapse) [9], prescribed therapy (efficacy, side effects, and burden of administration) [10], and non-disease-related factors [11–13]. Among non-disease related factors, an increasing body of literature is currently demonstrating the role psychosocial factors in affecting IBD patients’ HRQoL [12–16]. For instance, perceived stress has been found to be correlated to disease exacerbation, thus indirectly affecting patients’ HRQoL [17]. On the contrary, effective coping strategies help patients to more effectively adjust to adverse stressors, thus improving both clinical outcomes and satisfaction with life [11, 18]. On the other side, maladaptive coping behaviors such as self-blame, avoidance strategies are negatively correlated with patients’ HRQoL [11, 19, 20]. Other authors showed how self-image and the individuals’ ability to engage in intimate relationships – which are often compromised in patients with IBD—are important factors in their HRQoL [15]. Finally, some authors have also demonstrated the role of some personality traits in affecting the illness course [14, 21, 22]. In some studies, stable personality traits such as neuroticism and alexithymia were found to be related to IBD patients’ HRQoL, whereas social desirability was not [23, 24]. Another psychosocial aspect that research pointed out as worth to be investigated is that IBD patients’ adaptive attitudes towards the disease and its treatment make them more resilient and able to manage disease-related stressors [13, 25–28]. Particularly, among the adaptive attitudes that patients might enact, patient health engagement—described as the psychological readiness of individuals to become active player in their own healthcare management [29]—is more and more recognized to be a predictive factor of patient’s healthy behaviors and better clinical and psychological outcomes among chronic conditions such as IBD [30–37].

Goldring and colleagues, for instance, found that patients who were engaged in an active shared decision-making regarding their disease management with their doctor were more likely to report greater HRQoL [38]. Accordingly, Munson and colleagues provided some evidence that there are significant linkages between patients’ attitudes towards their care and their HRQoL [37]. Moreover, literature on chronic patients suggests that patients who report higher engagement in the care process are more likely to report better HRQoL scores [39–41].

However, to the best of our knowledge, no study has focused on the role of IBD patient health engagement in disease management in determining their HRQoL. According to these premises, with this study we aimed at detecting the role of the patients’ psychological readiness to be active player in their IBD management (i.e. patient health engagement) in affecting patient’s HRQoL.

Methods

Study design and population

A cross sectional online survey study has been conducted on a purposive, not representative sample of Italian patients diagnosed with IBD. The study was based on a semi-structured self-administered online questionnaire consisting of validated psychometrics scales and ad hoc items. More details on the questionnaire are provided in the following section.

Recruited patients belong to an IBD national-based Italian patient organization named “A.M.I.C.I. onlus” (Italian National Federation of Inflammatory Bowel Disease). They were invited—using mailing list of the patient organization A.M.I.C.I. onlus—to take part to this study between November 2016 and December 2017 and to complete and online survey distributed through the online platform Qualtrics®. No incentives were given to participants. Inclusion criteria were: age 18 years and older, diagnosed with IBD, and being able to read and understand the questionnaire.

Measures

The study questionnaire consisted of psychometric tools to address the research objectives. Moreover, we collected socio-demographics and clinical variables (age, gender, education, presence of children, employment, diagnosis, years from diagnosis, number of relapses). More details on the psychometric instruments implied in the study are provided in the following paragraphs.
**Patient health engagement: PHE-s Scale®**

The Italian version of the PHE-s scale® [42] was used to evaluate patients’ level of individual’s engagement in their health care management. The scale is based on the PHE model [43] which is a developmental psychological theory describing the patient’s experience of becoming active players in their healthcare pathway. According to this model, individuals may be differently engaged in care management according to their emotional, cognitive, and behavioral mindset [42]. Across the patient health engagement journey, while patients gain knowledge and information about their disease, they generally become more emotionally adjoined to their health condition and more confident in their ability to manage their disease.

The PHE-s scale® is able to grasp the complex psychological experience of the patient health engagement and has ordinal structure in order to be consistent with the PHE model’s conceptualization, which, through an algorithm which provides the final score, envisages four different positions along the engagement continuum: Blackout, Alert, Adhesion and Eudaimonic Project [29]. Specifically, patients have been considered with a “low PHE level” when they are positioned in Blackout or Alert, whereas they were defined as “high PHE level” when their scoring was related to the Adhesion and Eudaimonic positions (see Table 2). The scale is measured on a 7-point scale in order to facilitate patients’ responses and to avoid social desirability bias [42].

**Health-related quality of life: SIBD-Q**

Patients’ HRQoL has been measured through the Short Inflammatory Bowel Disease Questionnaire (SIBD-Q) [44, 45]. SIBD-Q is a validated and reliable tool which measures HRQoL in adult patients with IBD, UC, or CD. It contains 32 questions, divided into four HRQoL domains: bowel symptomatology (10 questions), systemic symptoms (5 questions), psycho-emotional function (12 questions), and social functioning (5 questions). For each question there are graded responses on a 7-point Likert scale, ranging from 1 (representing the "worst" aspect) to 7 (representing the "best" aspect). The four HRQoL domains are calculated as the mean of the questions referring to each specific health area and. The total SIBD-Q score ranges from 32 to 224, with higher scores reflecting better wellbeing. Finally, patients have been categorized as with a “low level of HRQoL” or with a “high level of HRQoL” for each domain, depending on the mean rate they reported: if it was above the median point of the Likert scale, they were considered as “high”, while if it was below, they were in a “low” position.

**Statistical analysis**

Statistical analysis has been run with the software IBM SPSS 23. Socio-demographic characteristic were analysed using descriptive and frequencies analysis. Preliminary, we tested the consistency of PHE-s® both as continuous and categorical variable and correlations were used to test any association between socio-demographic data and other variables. Secondly, to understand whether PHE-s® has a statistically significant effect on SIBD-Q total score and subscales when confounding variables—i.e. patients’ age, year of diagnosis and number of relapses, education, employment and presence of children—are controlled, a MANCOVA has been performed. Finally, we explored the relation between PHE-s® and SIBD-Q trough a simple linear regression model to understand the predictive power of patients’ health engagement on IBD patients’ HRQoL.

**Ethical considerations**

The study protocol was approved by the Ethics Commission of the Department of Psychology of the Catholic University of Milan (Italy). All patients involved in the study gave informed consent to participate.

**Results**

The sample involved in this study consisted of 1176 IBD patients. All the subjects that was present in the mailing list of the patient organization were contacted to fill out the online questionnaire. No data about who did not fill out the questionnaire were available. Socio-demographic data of people that completed the survey are showed in Table 1 and highlight an almost equal distribution between male and female participants, between those with and without children and a mean age of 45 years old. 51% has a high school degree and 86% is currently employed. The average number of disease relapses during the previous year is of 2, for a minimum of 0 and a maximum of 5 (see Table 1). Participants were also asked to report the number of years from the IBD diagnosis which ranged from 1 to 47 year(s).

Concerning the patient health engagement level, measured through the PHE-s®, about the half of the sample (47%) reported a low health engagement level (Blackout or Alert) (see Table 2). Moreover, 30% of the sample globally reported a low level of HRQoL: particularly, 29% reported problems concerning systemic symptoms and social functioning, and 23% felt impaired because of bowel symptomatology.
Nevertheless, the main issue for patients of this study seems to be the psycho-emotional functioning, that is considered the aspect of HRQoL most impacted by IBD in 37% of the sample (see Table 3).

Moreover, regarding socio-demographic and clinical variables and their association with HRQoL, the number reported disease relapses showed a negative association with the SIBD-Q: the higher number of

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**Table 1** Socio-Demographic and clinical characteristics of the sample (N = 1176)

|                        | Total          | Chron’s disease | Ulcerative colitis | Unclassified colitis |
|------------------------|----------------|-----------------|--------------------|----------------------|
|                        | N   | %   | N   | %   | N   | %   | N   | %   |
| Gender                 |     |     |     |     |     |     |     |     |
| Female                 | 365 | 48.3% | 189 | 25.0% | 171 | 22.6% | 2   | 0.3% |
| Male                   | 391 | 51.7% | 202 | 26.7% | 182 | 24.1% | 1   | 0.1% |
| Number of relapses (0-5) |      |       |      |       |      |       |      |       |
| 0                      | 236 | 33.0% | 0   | 0.0%  | 139 | 19.4% | 1   | 0.1% |
| 1                      | 172 | 24.1% | 1   | 0.1%  | 87  | 12.2% | 0   | 0.0% |
| 2                      | 86  | 12.0% | 2   | 0.3%  | 39  | 5.5%  | 0   | 0.0% |
| 3                      | 219 | 30.6% | 3   | 0.4%  | 105 | 14.7% | 2   | 0.3% |
| 5                      | 2   | 0.3%  | 5   | 0.7%  | 2   | 0.3%  | 0   | 0.0% |
| Number of relapses (0-5) |      |       |      |       |      |       |      |       |
| 0                      | 236 | 33.0% | 0   | 0.0%  | 139 | 19.4% | 1   | 0.1% |
| 1                      | 172 | 24.1% | 1   | 0.1%  | 87  | 12.2% | 0   | 0.0% |
| 2                      | 86  | 12.0% | 2   | 0.3%  | 39  | 5.5%  | 0   | 0.0% |
| 3                      | 219 | 30.6% | 3   | 0.4%  | 105 | 14.7% | 2   | 0.3% |
| 5                      | 2   | 0.3%  | 5   | 0.7%  | 2   | 0.3%  | 0   | 0.0% |
| Number of relapses (0-5) |      |       |      |       |      |       |      |       |
| 0                      | 236 | 33.0% | 0   | 0.0%  | 139 | 19.4% | 1   | 0.1% |
| 1                      | 172 | 24.1% | 1   | 0.1%  | 87  | 12.2% | 0   | 0.0% |
| 2                      | 86  | 12.0% | 2   | 0.3%  | 39  | 5.5%  | 0   | 0.0% |
| 3                      | 219 | 30.6% | 3   | 0.4%  | 105 | 14.7% | 2   | 0.3% |
| 5                      | 2   | 0.3%  | 5   | 0.7%  | 2   | 0.3%  | 0   | 0.0% |

**Table 2** Distribution of PHE-s® levels (%) in the study sample

| PHE-s® scores                  | Low level of Patient Engagement | High level of Patient Engagement |
|--------------------------------|--------------------------------|----------------------------------|
| Blackout                       | 7%                             | 40%                              |
| Alert                          | 42%                            | 11%                              |

Nevertheless, the main issue for patients of this study seems to be the psycho-emotional functioning, that is considered the aspect of HRQoL most impacted by IBD in 37% of the sample (see Table 3).

Moreover, regarding socio-demographic and clinical variables and their association with HRQoL, the number reported disease relapses showed a negative association with the SIBD-Q: the higher number of
Table 3 Health-related Quality of Life levels (%) in the four domains assessed by the SIBD-Q in the study sample

| Domain                     | Low level of Health-related Quality of Life (< median value) | High level of Health-related Quality of Life (> median value) |
|----------------------------|-------------------------------------------------------------|-------------------------------------------------------------|
| Psycho-Emotional Functioning| 37%                                                         | 63%                                                         |
| Bowel Symptoms              | 23%                                                         | 77%                                                         |
| Social Functioning          | 29%                                                         | 71%                                                         |
| Systemic Symptoms           | 29%                                                         | 71%                                                         |

relapses are referred, the lower SIBD-Q is, concerning total score ($r = -0.403; p < 0.001$), systemic symptoms ($r = -0.403; p < 0.001$), bowel symptoms ($r = -0.359; p < 0.001$), social ($r = -0.403; p < 0.001$) and psycho-emotional ($r = -0.334; p < 0.001$) functioning. Gender was significantly associated to HRQoL: male patients reported higher mean values of HRQoL than female patients. This effect is significant for SIBD-Q total score ($F = 14.67; p < 0.01$), as well as systemic symptoms ($F = 13.35; p < 0.01$), emotional functioning ($F = 9.26; p < 0.05$) and bowel-related symptoms ($F = 14.93; p < 0.01$) but not for social functioning. To understand the relationship between the level of patient health engagement (PHE-s®) and the level of patients’ HRQoL (SIBD-Q) and if this relationship was affected by confounding variables—patients’ age, years from diagnosis, number of relapses, presence of children education level and employment—a multivariate analysis of covariance (MANCOVA) has been performed. Table 4 shows results of the MANCOVA. MANCOVA showed that PHE-s® has a statistically significant association with SIBD-Q total score and subscales when all confounding variables are controlled ($F = 95.692; p < 0.01$) as well as with all SIBD-Q subscales. Nevertheless, the interaction between PHE-s® levels and gender is not statistically significant ($p > 0.05$). Similarly, the interaction between PHE-s® and the number of relapses in the last 12 months does not show any significance ($p > 0.05$).

Finally, a linear regression model has been run to understand the relationship that occurs between patient health engagement scores (PHE-s®) and patients’ HRQoL scores (SIBD-Q). Consistently with our hypothesis, this analysis pointed out that PHE-s® is significantly related to the SIBD-Q total score ($B = 0.582; p < 0.001; R^2 = 0.343$) and to the subscales’ scores—systemic symptoms ($B = 0.572; p < 0.001; R^2 = 0.327$), bowel symptoms ($B = 0.482; p < 0.001; R^2 = 0.232$), social ($B = 0.485; p < 0.001; R^2 = 0.234$) and psycho-emotional ($B = 0.607; p < 0.001; R^2 = 0.369$) functioning (see Table 5).

**Discussion**

This manuscript is based on a cross-sectional study undertaken among patients with IBD and the participants are members of a voluntary-based patient organization, AMICI. The aim of this study was to assess the effects of IBD patient’s level of health engagement on their HRQoL. The Italian version of the PHE-s® scale was used to evaluate patients’ level of health engagement. The SIBD-Q was administered to assess the HRQoL. The association between HRQoL and patient health engagement was assessed by performing MANCOVA and linear regression models. The main finding of this study is that patient health engagement, considered as the patients’ psychological readiness to play an active role in the healthcare process [29], is significantly associated with the level of patients’ HRQoL when socio-demographic and clinical confounding variables are controlled. Since PHE-s® level has been found to be related with SIBD-Q, we deepened the nature of this relationship by running a regression analysis. The regression model confirmed, in line with our hypothesis, the significant association of patient engagement and patients’ HRQoL levels after controlling for the other confounding variables such as demographics and clinical ones. This result is in line with other studies—conducted on different clinical populations—that have demonstrated how playing an active role in the self-management of the disease can be useful to improve many aspects concerning both patients’ HRQoL and disease severity [52, 53]. For example, Druss and colleagues [54] tested an intervention aimed at sustaining patients with mental health issues in their involvement in the healthcare process. In that study, experimental group showed significantly greater improvements in patient engagement than those in usual care, along with greater improvements in adherence, physical activity, and HRQoL. Barnes and colleagues have discovered that higher patient engagement in their care is associated with remission in patients with IBD [55].

Moreover, according to existing literature about factors impacting on IBD patients’ HRQoL of life, this study confirmed the significant association of socio-demographics (i.e. gender, age) [47, 48] and clinical variables (i.e. reported disease relapses) [49] with IBD patients’ HRQoL. Our results, appears in line with the ones by Sainsbury and colleagues [17] whose research underlined that not only clinical factors, but also socio-demographics—including gender and age—appear to be important in affecting patients’ HRQoL, suggesting that clinicians’ attention needs to be drawn towards those variables to improve efficiently IBD patients’ HRQoL. Some authors,
moreover, reported in their studies that IBD patients’ HRQoL was lower in patients who had hospitalization and more severe disease [50, 51]. Similarly, we found a correlation between the patients who reported many relapses and their HRQoL. This supports that disease severity have an impact on HRQoL. The discovery that patient health engagement has a significant relationship with patient’s HRQoL is one of the main strengths of this study and could have interesting practical implication in the development of interventions dedicated to enhancing patients’ wellbeing. Contrarily to socio-demographic and clinical characteristics that are factors more stable and difficult to modify, patient health engagement level can be modifiable through specific healthcare interventions.

Table 4 The MANCOVA model explaining PHE-s® and SIBD-Q association and the influence of socio-demographic and clinical variables. Only statistically significant socio-demographic and clinical variables have been included in the table

| Dependent Variable       | Sum of Squares | df | Mean Square | F     | p     |
|--------------------------|----------------|----|-------------|-------|-------|
| PHE-s® Levels            |                |    |             |       |       |
| SIBD-Q Total             | 264.66         | 3  | 88.221      | 95.629| < .001|
| SIBD-Q Systemic symptoms | 286.73         | 3  | 95.775      | 94.472| < .001|
| SIBD-Q Social Functioning| 293.71         | 3  | 97.905      | 56.848| < .001|
| SIBD-Q Bowel Symptoms    | 233.65         | 3  | 77.882      | 55.074| < .001|
| SIBD-Q Emotional functioning | 308.10     | 3  | 102.700     | 84.294| < .001|
| Gender                   |                |    |             |       |       |
| SIBD-Q Total             | 13.54          | 1  | 13.536      | 14.672| < .001|
| SIBD-Q Systemic symptoms | 13.51          | 1  | 13.506      | 13.351| < .001|
| SIBD-Q Social Functioning| 4.14           | 1  | 4.138       | 2.402 | 0.122 |
| SIBD-Q Bowel Symptoms    | 21.12          | 1  | 21.123      | 14.937| < .001|
| SIBD-Q Emotional functioning | 11.29       | 1  | 11.292      | 9.269 | 0.002 |
| Relapses in the last 12 moths |            |    |             |       |       |
| SIBD-Q Total             | 69.03          | 4  | 17.259      | 18.708| < .001|
| SIBD-Q Systemic symptoms | 79.19          | 4  | 19.796      | 19.568| < .001|
| SIBD-Q Social Functioning| 140.76         | 4  | 35.191      | 20.433| < .001|
| SIBD-Q Bowel Symptoms    | 73.76          | 4  | 18.439      | 13.039| < .001|
| SIBD-Q Emotional functioning | 45.61        | 4  | 11.403      | 9.359 | < .001|
| PHE-s®_Levels * Gender   |                |    |             |       |       |
| SIBD-Q Total             | 3.39           | 3  | 1.130       | 1.225 | 0.300 |
| SIBD-Q Systemic symptoms | 2.87           | 3  | 0.956       | 0.945 | 0.418 |
| SIBD-Q Social Functioning| 1.40           | 3  | 0.467       | 0.271 | 0.846 |
| SIBD-Q Bowel Symptoms    | 2.56           | 3  | 0.854       | 0.604 | 0.613 |
| SIBD-Q Emotional functioning | 5.85         | 3  | 1.951       | 1.601 | 0.188 |
| PHE-s®_Levels * Relapses in the last 12 moths | |   | | | |
| SIBD-Q Total             | 9.09           | 10 | 0.909       | 0.986 | 0.455 |
| SIBD-Q Systemic symptoms | 10.56          | 10 | 1.056       | 1.044 | 0.405 |
| SIBD-Q Social Functioning| 20.15          | 10 | 2.015       | 1.170 | 0.309 |
| SIBD-Q Bowel Symptoms    | 14.52          | 10 | 1.452       | 1.027 | 0.419 |
| SIBD-Q Emotional functioning | 8.13         | 10 | 0.813       | 0.667 | 0.755 |
| Gender * Relapses in the last 12 moths | |  | | | |
| SIBD-Q Total             | 6.51           | 3  | 2.171       | 2.353 | 0.071 |
| SIBD-Q Systemic symptoms | 6.84           | 3  | 2.281       | 2.255 | 0.081 |
| SIBD-Q Social Functioning| 9.83           | 3  | 3.276       | 1.902 | 0.128 |
| SIBD-Q Bowel Symptoms    | 9.61           | 3  | 3.204       | 2.266 | 0.080 |
| SIBD-Q Emotional functioning | 5.04         | 3  | 1.682       | 1.380 | 0.248 |
| PHE-s®_Levels * Gender * Relapses in the last 12 moths | |  | | | |
| SIBD-Q Total             | 7.67           | 7  | 1.096       | 1.188 | 0.308 |
| SIBD-Q Systemic symptoms | 7.29           | 7  | 1.041       | 1.029 | 0.410 |
| SIBD-Q Social Functioning| 13.00          | 7  | 1.857       | 1.078 | 0.376 |
| SIBD-Q Bowel Symptoms    | 5.14           | 7  | 0.734       | 0.519 | 0.820 |
| SIBD-Q Emotional functioning | 15.52        | 7  | 2.216       | 1.819 | 0.081 |
| Residuals                |                |    |             |       |       |
| SIBD-Q Total             | 466.80         | 506| 0.923       |       |       |
| SIBD-Q Systemic symptoms | 511.91         | 506| 1.012       |       |       |
| SIBD-Q Social Functioning| 871.45         | 506| 1.722       |       |       |
| SIBD-Q Bowel Symptoms    | 715.55         | 506| 1.414       |       |       |
| SIBD-Q Emotional functioning | 616.49       | 506| 1.218       |       |       |
In this sense, as this is a modifiable factor, screening for patient engagement levels, coupled with appropriate interventions to improve this psychosocial aspect, could improve care, and ultimately improve HRQoL outcomes among IBD patients [56].

In this sense, the level of patient health engagement can be considered as a precious element to rely on, both for predicting IBD patients’ HRQoL and for modifying it, to sustain patients’ wellbeing.

However, our study also has limitations. Given that the A.M.I.C.I. onlus is a voluntary-based patient organization, participants of this study (which were selected among those individuals belonging to the patient organization) may show higher levels of patient health engagement than the general IBD population, which may limit the generalizability of our results. Moreover, it is possible that patients in AMICI could be more prone to be active in their own disease in the first place, considering they are part of a patient organization. Another limitation is that—due to privacy issues—we have no data about who did not fill out the questionnaire and thus we cannot compare the characteristics of this population with the one that constituted our study sample. Moreover, we had not the possibility to know the whole number of patients who were firstly contacted to fill out the survey. Furthermore, even if with a limited number, our sample included people diagnosed with unclassified colitis. Further research should consider collecting more precise data about this diagnosis (i.e. number of patients with proctitis, left-sided and pancolitis). Finally, although the population of the study was recruited in all the Italian regions, we did not have access to other geographic or socioeconomic factors that may also influence patient engagement and/or patients’ HRQoL such as urban or rural contexts or income.

Conclusion

Patient health engagement is a novel concept in IBD research, and the study results suggest that IBD patients’ attitudes to play an active role in their healthcare may be a crucial factor in shaping HRQoL outcomes of this clinical population. Thus, our findings underline the importance of promoting patient health engagement initiatives to sustain patients’ HRQoL. Policy makers and clinicians—according to this study’s results—should increasingly recognize that patients can safeguard their HRQoL by being actively engaged in their health care. Indeed, successful patient health engagement is associated with a positive shift in the ways in which patients adjust to their illness condition and relate with their healthcare services, thus ultimately improving their own HRQoL.

Abbreviations

UC: Ulcerative Colitis; CD: Chron’s Disease; IBD: Inflammatory Bowel Disease; PHE-model: Patient Health Engagement Model; PHE-s®: Patient Health Engagement Scale; SIBD-Q: Short Inflammatory Bowel Disease Questionnaire; A.M.I.C.I. Onlus: Associazione Nazionale per le Malattie Infiammatorie Croniche dell’Intestino.

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Authors’ contributions

SB, EG and GG analyzed and interpreted the data, wrote the original draft, and reviewed and edited the various drafts of the manuscript. SL and EP were involved in the conception and the design of the study. SL, EP and GG revised the manuscript. All authors read and approved the final manuscript.

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Availability of data and materials

The datasets generated and/or analyzed during the current study are not publicly available due to data privacy reasons but are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate.

The ethics committee of Università Cattolica del Sacro Cuore (Italy) approved the study and written informed consent was obtained from all patients.

Consent for publication

The manuscript has been read and approved by authors, all the authors agree with the content of the manuscript and are aware of this submission.

Competing interests

The authors declare that they have no competing interests.

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| Table 5 Regression values of Patient Health Engagement (PHE-s®) on IBD patients’ HRQoL (SIBD-Q) |
|-----------------------------------------------|
| SIBD-Q                                       |
|      | Psycho-Emotional Functioning | Systemic symptoms | Bowel Symptoms | Social Functioning | Total Score |
|      | R squared | B   | R squared | B   | R squared | B   | R squared | B   | R squared |
| PHE-s® | .607      | .369 | .572      | .327 | .482      | .232 | .485      | .234 | .585      | .343 |

| Regression values of Patient Health Engagement (PHE-s®) on IBD patients’ HRQoL (SIBD-Q) |
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