Translation and evaluation of the simplified Chinese version of the rating form of IBD patient concerns

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Abstract

Background: Inflammatory bowel disease (IBD) has become a global public health problem. The prevalence of IBD in China increased annually in past two decades.

Methods: This study was to translate and validate the rating form of IBD patients’ concerns (RFIPC), and to describe disease-related worries and concerns of patients with IBD. The simplified Chinese version of the RFIPC was developed according to translation and back-translation procedure. Patients with IBD were consecutively enrolled from the First Affiliated Hospital of Guangzhou University of Chinese Medicine. The participants were assessed using the RFIPC and the Short Inflammatory Bowel Disease Questionnaire (SIBDQ). Internal consistency, test–retest reliability, measurement error, confirmatory factor analysis (CFA) and correlation of the RFIPC with the SIBDQ were performed to evaluate the psychometric characteristics of the RFIPC.

Results: A total of 116 patients with IBD, 73 with ulcerative colitis (UC) and 43 with Crohn’s disease (CD), were enrolled in this study. Thirty-seven of them recompleted the questionnaires for the second time between 7 and 14 days after the first interview. The results of CFA indicated the original structure of the RFIPC was reasonable. Cronbach’s alpha value of the RFIPC were 0.97. The intraclass correlation coefficients of four domains ranged from 0.85 to 0.92. The standard error of measurement was 7.10. The correlation coefficients between total score of the RFIPC and the SIBDQ score ranged from −0.54 to −0.70. Median total score of the RFIPC was 39.4 (IQR 24.0–59.3). Patients with severe symptoms reported higher scores of the RFIPC. The uncertain nature of disease, having surgery, having an ostomy bag, developing cancer, feeling out of control, being a burden on others and financial difficulties were highest concerns of patients with IBD. Comparing with patients with UC, patients with CD had more concerns of the ability to have children and being treated as different (P < 0.05).

Conclusions: The simplified Chinese version of RFIPC is a valid and reliable tool. It could be used for assessing disease-related worries and concerns of patients with IBD in China. Specific concerns of patients with UC and CD are different, therefore, health workers should consider the specific needs of UC and CD patients.

Keywords: Inflammatory bowel disease, The RFIPC, Translation, Validation

Background

Inflammatory bowel disease (IBD) is a chronic and disabling disease of the gastrointestinal tract characterized by episodes of intestinal inflammation [1]. Ulcerative colitis (UC) and Crohn’s disease (CD), the two primary forms
of IBD, are estimated to affect approximately 0.3% of the world's population [2]. A modeling study predicts that there will be a 1.5-fold increase for East Asia region with 4.5 million cases, and a 1.6-fold elevation in prevalence for high-income Asia-Pacific and Southeast Asia regions in 2035, as compared to 2020 [3].

IBD not only damages patient’s gastrointestinal tract, but also affects their mental health, causing depression and anxiety [4]. A high prevalence of psychological disorders was reported among patient with IBD in mainland China [5]. These psychological comorbidities increase disease burden and impair their quality of life directly [6–8]. Therefore, healthcare workers should be greater attention to the psychological burdens of patients with IBD.

The rating form of IBD patients’ concerns (RFIPC), developed by Drossman et al. in 1991, is a commonly used instrument to evaluate IBD patients’ disease-related worries and concerns [9]. It has been translated into 10 languages since its publication [10–17]. Currently, the RFIPC has been widely used in cross-sectional and prospective longitudinal studies [18, 19]. However, the RFIPC has not been translated into Chinese. The study aimed to translate the RFIPC into simplified Chinese and to evaluated its psychometric properties. Furthermore, we attempted to investigate disease-related worries and concerns among patients with IBD in mainland China.

Patients and methods
Patients

From June 2020 to June 2021, Chinese-speaking patients with IBD were consecutively invited from the First Affiliated Hospital of Guangzhou University of Chinese Medicine. Patients were eligible if they were between 16 and 75 years old, with an established diagnosis of UC or CD both by endoscopy and histological examination, classified according to the Montreal classification of inflammatory bowel disease [20]. The exclusion criteria were (1) patients with IBD who refused to participate in the study; (2) patients with severe cognitive impairment who could not understand the questionnaire; (3) patients with coexistent diseases (such as chronic heart failure, chronic renal failure, malignant tumours etc.) or neuropsychiatric disorders that can affect the results of the study. Trained researchers had face-to-face interview with eligible patients and invited them to participate in the study. Participants were asked to fill a set of questionnaires on the spot. The participants were asked to fill in the RFIPC and questionnaire about major symptoms (QMS) of IBD once again if they returned for further consultations between 7 and 14 days. All questionnaires were self-administered. Researchers would help explained the questions to participants when necessary.

Questionnaires

Demographic characteristics and medical information

Demographic characteristics of participants included gender, age, marital status, level of education, smoking and drinking. Medical information was about disease type, disease location, and the QMS of IBD. The QMS was regarded as an assessment of disease activity, including severity of abdominal pain, frequency of stool, level of fatigue, degree of weight loss. The questionnaire was self-administrated and recommended as an efficacy evaluation for treating colitis in Development of clinical trial of new drugs of traditional Chinese medicines published by the National Medical Product Administration of China [21]. Each symptom was rated on a four-point Likert scale from 0 (symptom not present) to 3 (severe). A higher score indicated a more severe symptom.

The simplified Chinese version of the RFIPC

The RFIPC is a 25-item questionnaire with each item scoring on a horizontal visual analogue scale 0–100 mm (0 = Not at all, 100 = A great deal). In the original questionnaire, 22 of 25 items were divided into four factors: disease impact, complications, sexual intimacy, and body stigma. An overall mean score of all items was as “sum score” [9].

After obtaining license from the original authors, the translation and back-translation process of the RFIPC were conducted in line with Brislin’s guidelines [22, 23]. First, two bilingual (Chinese and English) native experienced researchers translated the questionnaire from English to simplified Chinese independently. Then, the translation coordinator compared the two simplified Chinese version of the RFIPC and conduct a reconciliation process to produce the first draft. Second, the first draft of RFIPC was back-translated into English by two other bilingual researchers who were not involved in translation process. Thereafter, the coordinator discussed any discrepancies between the original source and the back-translated questionnaire with both forward and back translators. The subject “您的” (meaning “your”) was added to item “attractiveness”, “energy level”, “ability to perform sexually” for ease of understanding. Finally, the final version of the RFIPC was formed.

Cross-cultural adaptation of the final version of RFIPC was conducted using a pre-test. The pre-test involving 6 patients with IBD and 6 healthy controls aimed to identify any ambiguity in the items and wordings of the questionnaire. All subjects participated in the pre-testing completed the questionnaire in less than 10 min. They reported no difficulties in reading, understanding or answering the RFIPC. No change was made to the questionnaire after the pre-testing.
The short inflammatory bowel disease questionnaire (SIBDQ)

The SIBDQ is a short version of the Inflammatory Bowel Disease Questionnaire, and is used as a health-related quality-of-life measure of patients with IBD. The SIBDQ includes 10 questions grouped into 4 domains (bowel symptoms, systemic symptoms, social function, emotional function). All items are rated on a 7-point Likert scale (1=all the time, 7=never). The total score ranges from 10 to 70. A higher score indicates a better quality of life [24]. A simplified Chinese version of SIBDQ has been proofed to be a quick and reliable quality-of-life instrument for patients with IBD in mainland China [25].

Statistical analysis

All data from the questionnaires were pooled into Microsoft Office Excel 2016. The quality of a questionnaire's measurement properties was evaluated by the Consensus-based Standards for the selection of health Measurement Instruments (COSMIN) [26]. For normally distributed continuous variables, means and standard deviations (SD) were presented. Median and interquartile range (IQR) values were used to describe the nonnormally distributed continuous variables. Mann–Whitney U test or Kruskal–Wallis H test were used to compare medians of nonnormally distributed variables. The frequencies of categorical variables were compared using Pearson's Chi-square test or Fisher's exact test. All statistical tests were considered significant with \( P \leq 0.05 \). We performed all analyses using the Statistical Package for Social Sciences (SPSS 25.0, SPSS Inc., Chicago, IL, USA) and the IBM AMOS 24.0.

Confirmatory factor analysis (CFA) and Spearman's correlation coefficient \( (r_s) \) between the RFIPC and the SIBDQ was performed to evaluate validity. The goodness of fit of CFA model was assessed using root mean square error of approximation (RMSEA) and comparative fit index (CFI). RMSEA > 0.06, and CFI > 0.9 were recommended.

Reliability was tested by internal consistency and test–retest reliability. Cronbach's alpha coefficient values > 0.7 indicated strong internal consistency. The test–retest reliability was assessed using intraclass correlation coefficients (ICC). An ICC > 0.7 was considered as good reliability.

Measurement error was calculated using standard error of measurement (SEM) [27].

Scores of each domain for patients with different disease types and severity of major symptoms were compared in order to understand how disease types and disease activity affect patients' worries and burdens. The score of each item was compared in order to identify differences of concerns between patients with UC and CD.

Results

Participant characteristics

A total of 119 eligible patients were enrolled. Two of them refused to take part in the study. One patient was excluded because of missing data of medical information. At last, 116 patients were included for analysis. Among them, 37 patients were included for a second measurement. The mean age of 116 patients were 37.8 years (SD = 13.5 years), and 35.3% of them were women. The majority of patients had college degree and above (58.6%). More details of demographic characteristics were presented in Table 1.

Validity

The CFA of the original model (including 4 factors, Fig. 1) was performed. Chi-square, RMSEA, and CFI of model fit were 774.01, 0.16 and 0.80, respectively. These results suggested that original structure of the RFIPC was reasonable.

Total score of the RFIPC was moderate to high negatively correlated with the total SIBDQ score \( (r_s = -0.67, P < 0.001) \). The results of correlation between domains of RFIPC and SIBDQ were shown in Table 2. “Impact of disease” of the RFIPC had strong negative correlation with “emotional function” of the SIBDQ \( (r_s = -0.88) \).

Reliability

The Cronbach's alpha value for the RFIPC indicated an acceptable level of internal consistency \((\alpha = 0.97)\). Cronbach’s alpha for each domain of the RFIPC ranged from 0.83 to 0.96 (Table 2), indicating good internal reliability.

Thirty-seven participants, who returned to the hospital during 7–14 days after the first interview, filled in the RFIPC and the QMS for the second time. ICC of domains ranged from 0.85 to 0.92. The RFIPC showed high test–retest reliability (Table 3). They reported minor changes \((P > 0.05)\) of major symptoms during those days (Additional file 1: Table S1).

Measurement error

The standard deviation of the sample (both of the test and retest administration were pooled together) was 23.68. ICC of the total scores of the RFIPC was 0.91. The SEM of the RFIPC was 7.10.

Worries and concerns

Median total score of the RFIPC was 39.4 (IQR 24.0–59.3). Item “uncertain nature of disease” was the primary concern, follow by “having surgery”, “having an ostomy bag”, “developing cancer”, “feeling out of control”, “being a burden on others” and “financial difficulties”. Patients with severe symptoms, such as bloody stool and abdominal pain, reported higher scores in
Table 1  The characteristics of the included patients

|                          | IBD* (n = 116) | Test-retest (n = 37) | P-value |
|--------------------------|----------------|----------------------|---------|
| Sex                      |                |                      |         |
| Males (%)                | 75 (64.7)      | 28 (75.7)            | 0.213a  |
| Females (%)              | 41 (35.3)      | 9 (24.3)             |         |
| Age (mean ± SD)          | 37.8 ± 13.5    | 36.3 ± 13.2          | 0.550b  |
| Level of education       |                |                      |         |
| High school diploma or less (%) | 48 (41.4)  | 16 (43.2)           | 0.841a  |
| College degree and above (%) | 68 (58.6)  | 21 (56.8)           |         |
| Marital status           |                |                      |         |
| Married (%)              | 75 (64.7)      | 21 (56.8)            | 0.368a  |
| Single (%)               | 41 (35.3)      | 16 (43.2)            |         |
| Smoking                  |                |                      |         |
| Non-smoker (%)           | 73 (62.9)      | 23 (62.2)            | 0.354c  |
| Ex-smoker (%)            | 33 (28.4)      | 13 (35.1)            |         |
| Smoker (%)               | 10 (8.6)       | 1 (2.7)              |         |
| Drinking                 |                |                      |         |
| Yes (%)                  | 29 (25.0)      | 8 (21.6)             | 0.676a  |
| No (%)                   | 87 (75.0)      | 29 (78.4)            |         |
| Diagnosis                |                |                      |         |
| UC (%)                   | 73 (62.9)      | 21 (56.8)            | 0.502a  |
| CD (%)                   | 43 (37.1)      | 16 (43.2)            |         |
| Disease location of UC   |                |                      |         |
| Proctitis (%)            | 38 (33.0)      | 14 (37.8)            | 0.483c  |
| Left-sided colitis (%)   | 21 (18.3)      | 4 (10.8)             |         |
| Pancolitis (%)           | 14 (12.2)      | 3 (8.1)              |         |
| Disease location of CD   |                |                      |         |
| Small bowel (%)          | 25 (22.3)      | 10 (29.4)            | 0.492c  |
| Colon (%)                | 7 (6.2)        | 4 (11.8)             |         |
| Colon + small bowel (%)  | 11 (9.8)       | 2 (5.9)              |         |
| Diarrhea, times/day      |                |                      |         |
| Never                    | 49 (42.2)      | 17 (45.9)            | 0.630d  |
| < 3                      | 40 (34.5)      | 13 (35.1)            |         |
| 3–6                      | 22 (19.0)      | 5 (13.5)             |         |
| > 6                      | 5 (4.3)        | 2 (5.4)              |         |
| Bloody stools            |                |                      | 0.755d  |
| Never                    | 73 (62.9)      | 22 (59.5)            |         |
| Few                      | 35 (30.2)      | 13 (35.1)            |         |
| Mostly                   | 5 (4.3)        | 0 (0)                |         |
| Entire                   | 3 (2.6)        | 2 (5.4)              |         |
| Abdominal pain           |                |                      | 0.998d  |
| No                       | 19 (16.4)      | 7 (18.9)             |         |
| Mild                     | 57 (49.1)      | 16 (43.2)            |         |
| Moderate                 | 25 (21.6)      | 10 (27.0)            |         |
| Severe                   | 15 (12.9)      | 4 (10.8)             |         |
| Weight loss              |                |                      | 0.959d  |
| No                       | 39 (33.6)      | 12 (32.4)            |         |
| Mild                     | 25 (21.6)      | 9 (24.3)             |         |
| Moderate                 | 22 (19.0)      | 6 (16.2)             |         |
| Severe                   | 30 (25.8)      | 10 (27.0)            |         |

IBD inflammatory bowel disease, UC ulcerative colitis, CD Crohn’s disease

* P-value: Pearson’s Chi-Square; ^P-value: t-test; ^P-value: Likelihood ratio; ^P-value: Kruskal Wallis H test
all 4 domains of RFIPC (Table 4). No significant differences of total score and domain scores were found between patients with UC and CD. However, patients with CD had higher concerns of financial difficulties, the ability to have children, and being treated as different, when comparing to patients with UC ($P < 0.05$) (Table 5).

**Discussion**

The incidence and prevalence of IBD in China is increasing annually as a result of a rapid society transition culminating in a westernized environment [28]. The RIFPC is a quality-of-life instrument specified in measuring disease-related worries and concerns of IBD patients. To date, at least 10 different translated version of the RFIPC...
have been applied in research worldwide [10–17]. The RIFPC would help assessing disease-related worries and concerns of IBD patients in China.

The simplified Chinese version of the RFIPC is valid and reliable. The procedure of translation followed the guidelines of Brislin’s translation model [22, 23] and the validation study was carried out under guidance of the COSMIN [26]. Our results of CFA showed that the original structure of the RFIPC was appropriate. However, the model fit of this model was at the lower acceptable limit. Similarly, the authors of the Swedish version reported that the 4-factor model was a substantive improvement over the single-factor model, but still remain inadequate [29]. Both internal consistency and test–retest reliability of the RFIPC were good (Cronbach’s alpha = 0.97, ICC of domains: 0.85–0.92). These results were in accordance with some previous validation studies. For example, Cronbach’s alpha of the Greek version was 0.95, and ICC were 0.77–0.93 [15]. Cronbach’s alpha and ICC of the Swedish version were 0.95 and 0.79 respectively [12].

The importance of specific concerns varies among countries for the difference of social, cultural, and/or economic [13]. In this study, the uncertain nature of disease, having surgery, having an ostomy bag, developing cancer, feeling out of control, being a burden on others and financial difficulties were the highest concerns of patients with IBD were. In Greek, the unknown nature of disease was the primary concern, followed by feeling out of control, having access to quality medical care, fear of side effects (of medication), and energy level [15]. For patients with IBD in Spain, the five highest rated concerns were effects of medication, having an ostomy bag, the uncertain nature of disease, energy level, and developing cancer [16].

Even though UC and CD have similar burden and goals for treatment [30], there are some differences of disease-related worries and concerns. For patients with CD, they reported higher concerns of “ability to have children” and “being treated as different” when comparing with patients with UC (P < 0.05). Besides, “having an ostomy bag” was rated the highest score, since patients with CD may be at higher risk of needing a permanent ostomy, which was associated with reduced social role satisfaction [31]. Concern of “financial difficulties” seemed to be higher for CD patients, however, we did not investigate family economic conditions of the participants and their economic burden of IBD.

There were some limitations of our study. (1) Only 116 patients participated in this study. The results may be insufficient to generalize all the patients with IBD in mainland China. (2) The QMS questionnaire, which was solely used in China, was used as a measure of clinical activity in this study. Our results would be more convincing if the partial Mayo score and the Harvey-Bradshaw index, etc. were applied for assessing disease activity. (3) Content validity analysis was not included in this study. But, by using the RFIPC, the physician may be able to identify and rank concerns that may not otherwise be asked, or which patients may not volunteer,

### Table 2

| The RFIPC | Cronbach’s alpha | Correlation with the SIBDQ |
|-----------|------------------|---------------------------|
| Impact of disease | 0.96 | −0.66 |
| Complications | 0.94 | −0.51 |
| Sexual intimacy | 0.89 | −0.56 |
| Body stigma | 0.83 | −0.56 |
| Total RFIPC | 0.97 | −0.64 |

| Bowel symptoms | Social function | Emotional function | Systemic symptoms | Total SIBDQ |
|----------------|-----------------|--------------------|-------------------|------------|
| Impact of disease | 0.96 | −0.66 | −0.62 | −0.88 | −0.57 | −0.70 |
| Complications | 0.94 | −0.51 | −0.53 | −0.39 | −0.44 | −0.54 |
| Sexual intimacy | 0.89 | −0.56 | −0.49 | −0.47 | −0.48 | −0.57 |
| Body stigma | 0.83 | −0.56 | −0.51 | −0.40 | −0.45 | −0.56 |
| Total RFIPC | 0.97 | −0.64 | −0.61 | −0.54 | −0.55 | −0.67 |

### Table 3

| Domain | Visit 1 Median [IQR] | Visit 2 Median [IQR] | *P*-value | ICC | 95%CI |
|--------|----------------------|----------------------|------------|-----|-------|
| Impact of disease | 42.5 [22.2–57.2] | 43.1 [22.5–63.1] | 0.213 | 0.88 | 0.82–0.95 |
| Complications | 60.0 [28.8–71.3] | 45.0 [25.0–73.8] | 0.516 | 0.92 | 0.85–0.96 |
| Sexual intimacy | 26.7 [15.0–48.3] | 23.3 [15.0–33.3] | 0.847 | 0.85 | 0.72–0.92 |
| Body stigma | 30.0 [15.0–57.5] | 35.0 [10.0–70.0] | 0.150 | 0.86 | 0.75–0.93 |

*UC ulcerative colitis, CD Crohn’s disease, ICC intraclass correlation coefficient, CI confidence interval

*P*-value: Wilcoxon Signed Ranks test
but which are still important [9]. This finding could be a support to the content validity of the RFIPC. (4) Criterion validity analysis was not performed because no gold standards existed for quality-of-life instruments [32]. (5) The time period between the initial and the repeated administration was set between 7 to 14 days to ensure clinical condition of the participants did not change during those days. Though Terwee et al. point out that the 1 or 2 weeks will be appropriate [33], recall bias should be taken into account. A further study involving a larger sample size, as well as disease activity index, family economic conditions and costs, is needed in order to provide a more precise result.

Conclusions

The simplified Chinese version of RFIPC was translated according to the standard process for translating instruments. The RFIPC is a valid and reliable tool. It could be used for assessing disease-related worries and concerns of patients with IBD in China. The RFIPC was recommended by patients with IBD. Specific concerns of patients with UC and CD are different, therefore, health workers should consider the specific needs of UC and CD patients when working out strategies for treatment and disease management.

Table 4 The scores of RFIPC domains for patients with different disease types and severity of major symptoms

| Disease Type | Impact of disease | Complications | Sexual intimacy | Body stigma |
|--------------|-------------------|---------------|-----------------|-------------|
| **CD (n=43)** | **Median [IQR]**   | **Median [IQR]** | **Median [IQR]** | **Median [IQR]** |
| UC (n=73)    | 45.0 [22.5–69.4]   | 50.0 [22.5–90.0] | 30.0 [10.0–50.0] | 30.0 [15.0–60.0] |
| *P*-value    | 0.289              | 0.714          | 0.383           | 0.556       |
| **Diarrhea, times/day** |               |               |                 |             |
| Never (n=49) | 29.4 [19.4–50.6]   | 32.5 [20.0–65.0] | 20.0 [10.0–33.3] | 20.0 [10.0–35.0] |
| <3 (n=44)    | 41.6 [26.6–66.3]   | 61.3 [32.5–90.0] | 30.0 [16.7–55.0] | 32.5 [15.0–55.0] |
| 3–6 (n=22)   | 49.4 [37.5–58.1]   | 55.0 [35.0–77.5] | 36.7 [16.7–46.7] | 37.5 [25.0–50.0] |
| >6 (n=5)     | 70.6 [64.4–83.1]   | 77.5 [75.0–100.0] | 40.0 [40.0–100.0] | 50.0 [60.0–100.0] |
| *P*-value    | 0.003              | 0.003          | 0.050           | 0.001       |
| **Bloody stool** |             |               |                 |             |
| No (n=73)    | 28.8 [20.0–54.4]   | 37.5 [20.0–72.5] | 20.0 [10.0–40.0] | 25.0 [10.0–40.0] |
| Mild (n=35)  | 50.0 [40.6–57.5]   | 60.0 [45.0–86.3] | 40.0 [20.0–55.0] | 40.0 [20.0–55.0] |
| Moderate (n=5) | 83.1 [58.1–83.1]  | 100.0 [55.0–100.0] | 40.0 [35.0–100.0] | 40.0 [35.0–100.0] |
| Severe (n=3) | 64.4 [48.4–77.2]   | 77.5 [76.3–88.8] | 55.0 [55.0–77.5] | 55.0 [55.0–77.5] |
| *P*-value    | 0.001              | 0.002          | 0.006           | 0.003       |
| **Abdominal pain** |           |               |                 |             |
| No (n=19)    | 21.9 [17.2–37.2]   | 30.0 [13.8–43.8] | 10.0 [10.0–31.7] | 15.0 [10.0–20.0] |
| Mild (n=57)  | 35.6 [21.9–50.6]   | 45.0 [22.5–75.0] | 20.0 [10.0–30.0] | 25.0 [15.0–40.0] |
| Moderate (n=25) | 50.0 [37.5–68.1]  | 55.0 [42.5–72.5] | 43.3 [20.0–56.7] | 40.0 [30.0–55.0] |
| Severe (n=15) | 66.9 [58.4–85.6]   | 82.5 [76.3–100.0] | 63.3 [38.3–78.3] | 55.0 [47.5–90.0] |
| *P*-value    | <0.001             | <0.001         | <0.001          | <0.001      |
| **Weight loss** |             |               |                 |             |
| No (n=39)    | 29.4 [19.1–43.4]   | 37.5 [21.3–68.8] | 13.3 [10.0–30.0] | 20.0 [10.0–30.0] |
| Mild (n=25)  | 31.3 [22.5–45.6]   | 30.0 [20.0–52.5] | 16.7 [16.7–26.7] | 25.0 [15.0–40.0] |
| Moderate (n=22) | 49.4 [35.0–69.4]  | 55.0 [45.0–90.0] | 43.3 [20.0–53.3] | 37.5 [15.0–55.0] |
| Severe (n=30) | 55.0 [43.8–70.6]   | 75.0 [50.0–100.0] | 40.0 [26.7–70.0] | 52.5 [30.0–75.0] |
| *P*-value    | <0.001             | <0.001         | <0.001          | <0.001      |

UC ulcerative colitis, CD Crohn’s disease

* P-value: Mann–Whitney U test; ^P-value: Kruskal Wallis H test
### Table 5 Comparison of worries and concerns between patients with UC and CD

| Item                                         | Total (n = 113) | UC (n = 73) | CD (n = 43) | *P-value |
|----------------------------------------------|-----------------|-------------|-------------|----------|
| Financial difficulties                       | 50.0 [20.0–70.0] | 30.0 [20.0–60.0] | 50.0 [30.0–80.0] | 0.016    |
| Pain and suffering                           | 30.0 [20.0–60.0] | 30.0 [20.0–60.0] | 40.0 [20.0–70.0] | 0.256    |
| Ability to achieve full potential            | 40.0 [20.0–60.0] | 40.0 [20.0–60.0] | 40.0 [20.0–70.0] | 0.467    |
| Loss of bowel control                        | 30.0 [20.0–60.0] | 30.0 [20.0–50.0] | 40.0 [20.0–70.0] | 0.277    |
| Developing cancer                            | 50.0 [20.0–90.0] | 50.0 [30.0–90.0] | 50.0 [20.0–85.0] | 0.668    |
| Dying early                                  | 40.0 [20.0–70.0] | 40.0 [20.0–60.0] | 40.0 [20.0–80.0] | 0.729    |
| Being a burden on others                     | 50.0 [30.0–80.0] | 40.0 [30.0–70.0] | 60.0 [30.0–85.0] | 0.148    |
| Attractiveness                               | 30.0 [20.0–60.0] | 30.0 [20.0–60.0] | 50.0 [20.0–70.0] | 0.263    |
| Feeling alone                                | 30.0 [20.0–50.0] | 30.0 [20.0–50.0] | 20.0 [20.0–55.0] | 0.716    |
| Feeling out of control                       | 50.0 [30.0–72.5] | 50.0 [30.0–70.0] | 50.0 [25.0–80.0] | 0.641    |
| Feeling “dirty” or “smelly”                  | 30.0 [10.0–50.0] | 30.0 [20.0–50.0] | 30.0 [10.0–60.0] | 0.940    |
| Ability to perform sexually                  | 50.0 [20.0–70.0] | 40.0 [10.0–40.0] | 30.0 [10.0–65.0] | 0.503    |
| Ability to have children                     | 20.0 [10.0–50.0] | 20.0 [10.0–50.0] | 30.0 [10.0–75.0] | 0.012    |
| Passing the disease to others                | 20.0 [10.0–50.0] | 20.0 [10.0–50.0] | 20.0 [10.0–60.0] | 0.641    |
| Being treated as different                   | 30.0 [10.0–40.0] | 20.0 [10.0–40.0] | 30.0 [20.0–50.0] | 0.016    |
| Having surgery                               | 50.0 [27.5–82.5] | 50.0 [30.0–80.0] | 50.0 [25.0–95.0] | 0.307    |
| Having an ostomy bag                         | 50.0 [20.0–90.0] | 50.0 [20.0–90.0] | 70.0 [25.0–100.0] | 0.266    |
| Producing unpleasant odors                  | 20.0 [10.0–52.5] | 20.0 [10.0–50.0] | 30.0 [10.0–60.0] | 0.203    |
| Energy level                                 | 40.0 [20.0–70.0] | 40.0 [20.0–60.0] | 40.0 [20.0–75.0] | 0.712    |
| Feelings about my body                       | 40.0 [20.0–70.0] | 40.0 [20.0–60.0] | 30.0 [20.0–75.0] | 0.954    |
| Intimacy                                     | 20.0 [10.0–50.0] | 20.0 [10.0–40.0] | 20.0 [10.0–60.0] | 0.355    |
| Loss of sexual drive                         | 20.0 [10.0–50.0] | 20.0 [10.0–40.0] | 20.0 [10.0–55.0] | 0.343    |
| Having access to quality medical care        | 40.0 [20.0–60.0] | 40.0 [20.0–60.0] | 30.0 [20.0–75.0] | 0.682    |
| Uncertain nature of my disease               | 60.0 [30.0–90.0] | 60.0 [30.0–90.0] | 70.0 [30.0–90.0] | 0.961    |
| Effects of medication                        | 50.0 [20.0–80.0] | 50.0 [20.0–80.0] | 50.0 [30.0–80.0] | 0.452    |
| Total score                                  | 39.4 [24.0–59.3] | 38.4 [24.8–54.4] | 42.0 [21.4–68.4] | 0.360    |

UC: ulcerative colitis, CD: Crohn’s disease, IQR: interquartile range

*P-value: Mann–Whitney U test

### Abbreviations

IBD: Inflammatory bowel disease; UC: Ulcerative colitis; CD: Crohn’s disease; RFIPC: Rating form of IBD patients’ concerns; SIBDQ: The Short Inflammatory Bowel Disease Questionnaire; QMS: Questionnaire about major symptoms; CFA: Confirmatory factor analysis; CI: Confidence interval; COSMIN: Consensus-based Standards for the selection of health Measurement Instruments; SD: Standard deviation; IQR: Interquartile range; RMSEA: Root Mean Square Error of Approximation; CFI: Comparative Fit Index; ICC: Intraclass correlation coefficient; SEM: Standard error of measurement.

### Supplementary Information

The online version contains supplementary material available at [https://doi.org/10.1186/s12876-022-02503-7](https://doi.org/10.1186/s12876-022-02503-7).

**Additional file 1. Table S1.** Comparison of the major symptoms of the 37 test-retested IBD patients (16 with CD and 21 with UC).

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**Author contributions**

Statistical analysis and manuscript drafting: JL, SZ, JZ. Patients enrolling, field survey and data input: JH, JK, HbL, and HwL. Data proofreading and management: HwL and LZ. XC and FL designed this study and took the responsibility for supervision. All authors read approved the final manuscript.

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References
1. Guan Q. A comprehensive review and update on the pathogenesis of inflammatory bowel disease. J Immunol Res. 2019;2019:7247238.
2. Ng SC, Shi HY, Hamidi N, Underwood FE, Tang W, Benchimol EI, Panacchione R, Ghosh S, Wu J, Chan F, et al. Worldwide incidence and prevalence of inflammatory bowel disease in the 21st century: a systematic review of population-based studies. Lancet. 2017;390(10114):2769–78.
3. Ofliatifar M, Zali MR, Pourhoseingholi MA, Balaii H, Ghavami SB, Ivanchuk P, Nazari SH, Shahrokh S, Sabour S, et al. The emerging epidemic of inflammatory bowel disease in Asia and Iran by 2035: a modeling study. BMC Gastroenterol. 2021;21(1):204.
4. Barbeno B, Zamani M, Black CJ, Savarino EV, Ford AC. Prevalence of symptoms of anxiety and depression in patients with inflammatory bowel disease: a systematic review and meta-analysis. Lancet Gastroenterol Hepatol. 2021;6(5):359–70.
5. Hu S, Chen Y, Chen Y, Wang C. Depression and anxiety disorders in patients with inflammatory bowel disease. Front Psychiatry. 2021;12:74057.
6. Szigethy E, Murphy SM, Ehrlich OG, Engel-Nitz NM, Heller CA, Henricksen K, Lawton R, Meadows P, Allen JI. Mental health costs of inflammatory bowel diseases. Inflamm Bowel Dis. 2021;27(1):40–8.
7. Zhao E, Yu Q, Ali A, Mu Y, Shi Y, Zhu L. Effects of standard treatments on depressive anxiety symptoms in patients with inflammatory bowel disease: a systematic review and meta-analysis. Gen Hosp Psychiatry. 2022;74:118–25.
8. Fu H, Kaminga AC, Peng Y, Feng T, Wang T, Wu X, Yang T. 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(1):11.
9. Drossman DA, Leserman J, Li ZM, Mitchell CM, Zagami EA, Patrick DL. The rating form of IBD patient concerns: a new measure of health status. Front Psychiatry. 2017;8:504.
10. Moser G, Tillinger W, Sachs G, Genser D, Maier-Dobersberger T, Spiess K, Wyatt J, Vogelsang H, Lochs H, Gangl A. Disease-related worries and concerns: a study on out-patients with inflammatory bowel disease. Eur J Gastroenterol Hepatol. 1995;7(9):853–8.
11. Colombel JF, Yazdanpanah Y, Laurent F, Houcke P, Delays N, Marquis P. Quality of life in chronic inflammatory bowel diseases: Validation of a questionnaire and first French data. Gastroenterol Clin Biol. 1996;20(12):1071–7.
12. Hjortswang H, Strom M, Almeida RT, Almer S. Evaluation of the RFIPC, a disease-specific health-related quality of life questionnaire, in Swedish patients with ulcerative colitis. Scand J Gastroenterol. 1997;32(12):1235–40.
13. Leventen S, Li Z, Almer S, Barbosa A, Marquis P, Moser G, Sperber A, Toner B, Drossman DA. Cross-cultural variation in disease-related concerns among patients with inflammatory bowel disease. Am J Gastroenterol. 2001;96(6):1822–30.
14. Jelness-Jørgensen LP, Møn B, Bernklau T. Worries and concerns among inflammatory bowel disease patients followed prospectively over one year. Gastroenterol Res Pract. 2011;2011:492034.
15. Argyrou N, Roma E, Kapsountakis A, Tsakiridou E, Oikonomou K, Manolakis A, Potamianos S. The rating form of IBD patient concerns: translation, validation, and first implementation of the Greek version. Gastroenterol Res Pract. 2017;2017:6267175.
16. Berroa DL, Mora CN, Fernandez SL. The concerns of Spanish patients with inflammatory bowel disease as measured by the RFIPC questionnaire. Rev Esp Enferm Dig. 2017;109(3):196–201.
17. Walentywicz M, Van de Pauw I, Coenen S, Fierens L, Vlaeyen J, von Ludwolt A, Van Oudenhove L, Vermeire S, Van Assche G, Ferrante M, et al. Worries and concerns of inflammatory bowel disease (IBD) patients in Belgium—a validation of the Dutch rating form. Scand J Gastroenterol. 2020;55(12):1427–32.
18. Stjernman H, Tysk C, Almer S, Strom M, Hjortswang H. Worries and concerns in a large unsolicited cohort of patients with Crohn's disease. Scand J Gastroenterol. 2010;45(6):606–706.
19. Blouidel-Kucharski F, Chicrop C, Marquis P, Cortot A, Baron F, Gendre JP, Colombel JF. Health-related quality of life in Crohn's disease: a prospective longitudinal study in 231 patients. Am J Gastroenterol. 2001;96(10):2915–20.
20. Satiani J, Silverberg MS, Vermeire S, Colombel JF. The Montreal classification of inflammatory bowel disease: controversies, consensus, and implications. Gut. 2006;55(6):749–53.
21. Yang ZQ, Tang YQ, Du YP, Tang HM, Zhang L, Gao R, Hu SY, Tang JY, Yuan WA. Development of clinical trial of new drugs of traditional Chinese medicines. Zhongguo Zhong Yao Za Zhi. 2021;46(7):1691–6.
22. Jones PS, Lee JW, Phillips LR, Zhang XY, Jaceldo KB. An adaptation of Brislin's translation model for cross-cultural research. Nurs Res. 2001;50(5):300–4.
23. Bullinger M, Alonso J, Apolone G, Leplege A, Sullivan M, Wood-Dauphinee S, Gandeck B, Wagner A, Aaronson N, Bech P, et al. Translating health status questionnaires and evaluating their quality: the IQOLA Project approach. International Quality of Life Assessment. J Clin Epidemiol. 1998;51(11):913–23.
24. Irvine EJ, Zhou Q, Thompson AK. The Short Inflammatory Bowel Disease Questionnaire: a quality of life instrument for community physicians managing inflammatory bowel disease CCRPT Investigators. Canadian Crohn's Relapse Prevention Trial. Am J Gastroenterol. 1996;91(8):1571–8.
25. Zhang SJ, Luo JF, Peng B, Hou JT, Xu Q, Chen LX, Li HB, Liu SY, Zhong JM, He ZF, et al. Reliability and validity of the Chinese version of the short inflammatory bowel disease questionnaire. World Chin J Digestol. 2022;30(1):17–23.
26. Prinsen C, Molink KB, Bouter LM, Alonso J, Patrick DL, de Vet H, Terwee CB. COSMIN guideline for systematic reviews of patient-reported outcome measures. Qual Life Res. 2018;27(5):1147–57.
27. Molink KB, Boers M, van der Vleuten C, Bouter LM, Alonso J, Patrick DL, de Vet H, Terwee CB. COSMIN Risk of Bias tool to assess the quality of studies on reliability or measurement error of outcome measurement instruments: a Delphi study. BMC Med Res Methodol. 2020;20(1):293.
28. Kaplan GG, Ng SC. Globalisation of inflammatory bowel disease: perspectives from the evolution of inflammatory bowel disease in the UK and China. Lancet Gastroenterol Hepatol. 2016;1(4):307–16.
29. Jaghult S, Saboouchi F, Johansson UB, Wredling R, Kapraali M. Factor structures of the Swedish Version of the RFIPC. Investigating the Validity of Measurements of IBD Patients’ Worries and Concerns. Gastroenterol Res. 2010;3(5):191–200.
30. Le Berre C, Ananthakrishnan AN, Danese S, Singh S, Peyrin-Biroulet L. Ulcerative colitis and Crohn’s disease have similar burden and goals for treatment. Clin Gastroenterol Hepatol. 2020;18(1):14–23.

31. Abdalla MI, Sandler RS, Kappelman MD, Martin CF, Chen W, Anton K, Long MD. The impact of ostomy on quality of life and functional status of Crohn’s disease patients. Inflamm Bowel Dis. 2016;22(11):2658–64.

32. Mokkink LB, Terwee CB, Knol DL, Stratford PW, Alonso J, Patrick DL, Bouter LM, de Vet HC. The COSMIN checklist for evaluating the methodological quality of studies on measurement properties: a clarification of its content. BMC Med Res Methodol. 2010;10:22.

33. Terwee CB, Bot SD, de Boer MR, van der Windt DA, Knol DL, Dekker J, Bouter LM, de Vet HC. Quality criteria were proposed for measurement properties of health status questionnaires. J Clin Epidemiol. 2007;60(1):34–42.

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