

Validity and reliability of the Indonesian version of the 9-item Inflammatory Bowel Disease Questionnaire (IBDQ-9)

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ABSTRACT

BACKGROUND Decreasing the quality of life (QoL) of patients with inflammatory bowel disease (IBD) will increase morbidity and mortality. A valid and reliable instrument is needed to assess the QoL of patients with IBD. This study aimed to analyze the validity and reliability of the Indonesian version of the 9-item Inflammatory Bowel Disease Questionnaire (IBDQ-9).

METHODS This cross-sectional study was conducted using the Indonesian version of the IBDQ-9 in adult patients with IBD at the Gastroenterology Outpatient Clinic, Cipto Mangunkusumo Hospital, Jakarta, in November 2022. Patients aged 18 to 59 years who had experienced IBD for at least 2 weeks and provided informed consents were included. The total score of the IBDQ-9 Indonesian version was compared with the 36-item Short-Form Health Survey (SF-36) using the Spearman's correlation test. Reliability tests were examined using Cronbach's alpha and the intraclass correlation coefficient (ICC).

RESULTS A total of 124 participants were included in this study. The Spearman's test showed a high and significant result for the IBDQ-9 Indonesian version and the SF-36 ($r = 0.769$ and $p < 0.001$). Cronbach's alpha and ICC coefficient were equal to 0.883.

CONCLUSIONS This study provided evidence of the good validity and reliability of the IBDQ-9 Indonesian version for assessing the QoL of patients with IBD in Indonesia.

KEYWORDS inflammatory bowel disease, quality of life

Inflammatory bowel disease (IBD) is a chronic digestive tract inflammatory condition categorized into Crohn's disease (CD), ulcerative colitis (UC), and indeterminate colitis.¹ The incidence has increased in Asian countries, including Indonesia, over the last two decades. Patients with IBD have poorer quality of life (QoL) than healthy controls. However, Indonesia does not yet have an instrument to specifically measure the QoL of patients with IBD.^{2,3}

Hitherto, QoL in Indonesia has been measured using generic instruments, such as the 36-item Short-Form Health Survey (SF-36), which account for various respondent conditions. The SF-36 is widely used to

assess QoL in healthy and diseased populations because it shows good results. However, in assessing the QoL of patients with IBD, several psychometric aspects of the SF-36 may have affected the interpretation of the results. The SF-36 may have limitations in measuring changes in QoL over time based on IBD activity. The SF-36 also does not have an IBD-specific domain related to the severity of gastrointestinal symptoms, which is a risk factor for decreased QoL in patients with IBD. This allows for a floor or ceiling effect in assessing the QoL of patients with IBD using the SF-36. Additionally, the relatively large number of SF-36 questions (36 items) is considered inefficient for each outpatient visit.⁴

Accordingly, an IBD-specific QoL evaluation tool, such as the 9-item Inflammatory Bowel Disease Questionnaire (IBDQ-9), is required in Indonesia. The IBDQ-9 is a self-rated instrument consisting of nine questions representing four domains of QoL: gastrointestinal, systemic, emotional, and social symptoms. The IBDQ-9 is a short form of the IBDQ-36 compiled by Alcalá et al⁵ and is the gold standard for examining the QoL of patients with IBD. The validity of the IBDQ-9 showed a high correlation ($r = 0.91$, $p < 0.01$) when compared with the IBDQ-36.⁵ With all the advantages of the IBDQ-9 over the SF-36, this study aimed to determine the validity and reliability of the Indonesian version of the IBDQ-9 to assess the QoL of patients with IBD.

METHODS

This cross-sectional study was conducted online at the Gastroenterology Outpatient Clinic of the Department of Internal Medicine, Faculty of Medicine, Universitas Indonesia, Cipto Mangunkusumo Hospital, in November 2022. The minimum required sample size was 90 participants, determined using a rule of thumb. Patients with a history of IBD who had been on an outpatient basis at the Gastroenterology Outpatient Clinic for more than 2 weeks, aged 18 to 59 years, proficient in Indonesian, and could read and write with or without aids were included in the study. All the participants provided informed consent. This study was approved by the Ethics Committee of the Faculty of Medicine, Universitas Indonesia – Cipto Mangunkusumo Hospital (No: KET-1072/UN2.F1/ETIK/PPM.00.02/2022).

As shown in the Supplementary File, the IBDQ-9 was translated into Indonesian and back-translated into English by independent translators from two different institutions. The results of the IBDQ-9 translation were discussed with four gastroenterology experts to create an appropriate instrument for the Indonesian sociocultural elements. The IBDQ-9 English version was returned to Dr. Francesc Casellas, the instrument's owner, and received no feedback regarding its suitability. Based on this, the Indonesian version of the IBDQ-9 was used for pilot testing in 20 patients with IBD (Supplementary Table 1). Validity and reliability tests were performed using a larger sample size. Data, including sociodemographic and clinical characteristics of the disease, are presented

in a table of proportions. Content validity analysis was performed using the content validity index (CVI), and correlation coefficient assessment for construct validity was performed using Pearson's or Spearman's correlation tests. Internal consistency reliability was assessed by determining Cronbach's alpha and test-retest reliability using the intraclass correlation coefficient (ICC).

RESULTS

Among the 132 participants who completed the Indonesian versions of the SF-36 and IBDQ-9, 8 were excluded because they were unwilling to sign the informed consent form. Complete data are presented in Table 1.

The Indonesian version of the IBDQ-9 showed good content validity (Table 2). This assessment was qualitatively determined by a panel of experts who evaluated each instrument item. The quantitative approach for CVI scored 1 because all experts gave scale scores of 3 and 4.

Overall, the average total score for the Indonesian version of the IBDQ-9 was 37.3 (10.93) points, with a median of 38 (15–61) points. Good QoL was expressed by a cut-off point of >27 points (on a scale of 63) or >50.2 points (on a scale of 100) on the total score of the Indonesian version of the IBDQ-9 instrument; thus, 96 (77.4%) participants were assessed for their QoL (Table 3; Supplementary Figure 1).

Table 1. Characteristics of the participants

| Characteristics | n (%) (N = 124) |
|-----------------|-----------------|
| Age (years) | |
| 18–24 | 11 (8.9) |
| 25–44 | 73 (58.9) |
| 45–59 | 40 (32.3) |
| Male sex | 33 (26.6) |
| Residence | |
| Urban | 95 (76.6) |
| Rural | 29 (23.4) |
| Ethnicity | |
| Javanese | 48 (38.7) |
| Sundanese | 26 (21.0) |
| Chinese | 9 (7.3) |
| Batakese | 7 (5.6) |

Table continued on next page

Table 1. (Continued)

| Characteristics | n (%) (N = 124) |
|--|-----------------|
| Betawinese | 8 (6.5) |
| Ambonese | 4 (3.2) |
| Minangnese | 9 (7.3) |
| Others* | 13 (10.5) |
| Education | |
| Elementary | 5 (4.0) |
| Junior high school | 3 (2.4) |
| Senior high school | 45 (36.3) |
| Bachelor | 64 (51.6) |
| Postgraduate | 6 (4.8) |
| Doctorate | 1 (0.8) |
| Employment | |
| Employee | 70 (56.5) |
| Unemployee | 54 (43.5) |
| Good support systems | |
| Yes | 105 (84.7) |
| No | 19 (15.3) |
| Diagnosis duration (years) | |
| 0–5 | 112 (90.3) |
| 6–10 | 8 (6.5) |
| 11–15 | 2 (1.6) |
| >15 | 2 (1.6) |
| Type of IBD | |
| CD | 49 (39.5) |
| UC | 43 (34.7) |
| IC | 32 (25.8) |
| Treatment history | |
| Mesalamine | 87 (70.2) |
| Combination | 30 (24.2) |
| Steroid | 1 (0.8) |
| Others† | 6 (4.8) |
| History of other diseases | |
| Autoimmune | 23 (18.5) |
| Infection | 4 (3.2) |
| Malignancy | 4 (3.2) |
| Others‡ | 70 (56.5) |
| None | 23 (18.5) |
| Surgical history post IBD diagnosis | 10 (8.1) |
| Hospitalization prior to IBD treatment | 76 (61.3) |
| Hospitalization after IBD treatment | 59 (47.6) |

IBD=inflammatory bowel disease; IC=indeterminate colitis; CD=Crohn's disease; UC=ulcerative colitis

*Other ethnicities were Timornese, Arabianese, Malaynese, Minahasanese; †other treatments such as methotrexate and biologic agent; ‡other diseases were psychosomatic, gastroenterology, hematology, and degenerative diseases

Analysis of the IBDQ-9 Indonesian version's total score showed a high correlation with the total score of the SF-36 Indonesian version (correlation coefficient value of 0.769, $p < 0.001$) using the Spearman's correlation test (Supplementary Table 2). A high correlation was also observed when analyzing each IBD diagnosis using Spearman's correlation test ($r_s = 0.792$, $p < 0.001$) (Supplementary Table 3).

This study also compared the QoL of patients with IBD in Indonesia using the validated SF-36 instrument (Supplementary Table 4). In the SF-36 instrument, a good QoL was expressed by a cut-off point of >50 points for the total score of the Indonesian version of the SF-36 instrument; thus, 52 (41.9%) participants were declared to have a good QoL.

The Indonesian version of the IBDQ-9, as measured by internal consistency and test-retest reliability, also showed good results. The IBDQ-9 Indonesian version had a Cronbach's alpha value of 0.883, indicating that all the questions were effectively integrated into the instrument. In addition, the test-retest reliability of the IBDQ-9 Indonesian version was included in the "good" category based on the ICC value of 0.883 (95% confidence interval [CI] = 0.849–0.912).

DISCUSSION

This study tested the validity and reliability of the IBDQ-9 Indonesian version to assess the QoL of patients with IBD in Indonesia. A specialized instrument with specific indicators of bowel movements and digestive complaints is required to assess the QoL in patients with IBD. Patients with active IBD tend to have more gut symptoms that interfere with daily activities, as well as more illness concerns, perceived stress, and emotional distress. However, poor QoL is not limited to active episodes; even during remission, patients with IBD may experience anxiety relapse, which lowers their QoL. QoL was assessed using the IBDQ-9 Indonesian version. The total score of the IBDQ-9 showed a statistically significant correlation with the total score of the SF-36. This result is in accordance with the results of the IBDQ-9 validation test in Iran by Gholamrezaei et al,⁶ which showed a significant correlation with the SF-36 ($r = 0.524$, $p < 0.001$). In addition, this study assessed the instrument's reliability by measuring its internal consistency and test-retest reliability. The internal consistency assessment results were good and aligned with the IBDQ-9 Spanish version by Alcalá

Table 2. CVI of the IBDQ-9 Indonesian version

| Domains | Questions | Expert 1 | Expert 2 | Expert 3 | Expert 4 | I-CVR | CVR |
|---------------------------|------------|----------|----------|----------|----------|-------|-----|
| Gastrointestinal symptoms | Q1 | 3 | 4 | 3 | 4 | 1 | 1 |
| | Q5 | 3 | 4 | 4 | 4 | 1 | 1 |
| | Q7 | 3 | 4 | 3 | 4 | 1 | 1 |
| | Q8 | 3 | 4 | 4 | 4 | 1 | 1 |
| Systemic symptoms | Q2 | 3 | 4 | 4 | 4 | 1 | 1 |
| | Q3 | 3 | 4 | 4 | 4 | 1 | 1 |
| | Q6 | 3 | 4 | 4 | 4 | 1 | 1 |
| Social function | Q4 | 3 | 4 | 3 | 4 | 1 | 1 |
| Emotional function | Q9 | 3 | 4 | 3 | 4 | 1 | 1 |
| | Mean I-CVI | 1 | 1 | | | | |
| | S-CVI/UA | 1 | 1 | | | | |
| | S-CVI/Ave | 1 | 1 | | | | |

Ave=average method; IBDQ-9=9-item Inflammatory Bowel Disease Questionnaire; I-CVI=item content validity index; I-CVR=item content validity ratio; CVI=content validity index; CVR=content validity ratio; S-CVI=scale content validity index; UA=universal average method

Table 3. Characteristics of IBD patients' QoL score with the IBDQ-9 Indonesian version

| Score | Average | Median | Min | Max |
|-----------------------------|---------|--------|-------|-------|
| Q1 | 5.43 | 6.00 | 1.00 | 7.00 |
| Q2 | 3.15 | 3.00 | 1.00 | 7.00 |
| Q3 | 4.31 | 5.00 | 1.00 | 7.00 |
| Q4 | 4.28 | 4.00 | 1.00 | 7.00 |
| Q5 | 4.04 | 4.00 | 1.00 | 7.00 |
| Q6 | 3.56 | 3.50 | 1.00 | 7.00 |
| Q7 | 4.57 | 5.00 | 1.00 | 7.00 |
| Q8 | 3.81 | 4.00 | 1.00 | 7.00 |
| Q9 | 4.15 | 5.00 | 1.00 | 7.00 |
| Total score | 37.30 | 38.00 | 15.00 | 61.00 |
| Total score (max scale 100) | 57.31 | 57.40 | 36.70 | 86.30 |

IBD=inflammatory bowel disease; IBDQ-9=9-item Inflammatory Bowel Disease Questionnaire; QoL=quality of life

et al⁵ (Cronbach's alpha = 0.95 in UC and 0.91 in CD). Gholamrezaei et al⁶ also reported an equally good internal consistency value, with a Cronbach's alpha of 0.76.

Patients with active disease have significantly impaired health-related QoL (HRQoL) compared with patients in remission. In contrast, achieving disease remission in CD, either pharmacologically or surgically, is associated with improved HRQoL. Importantly, poor HRQoL is not limited to active episodes alone; it persists even when the disease is inactive.⁶⁻¹²

The interaction of various factors, such as genetic susceptibility and changes in the environment of the gastrointestinal tract, is thought to play a role in

impaired gastrointestinal immunity, which causes damage to the gastrointestinal tract.¹⁻³ This damage in IBD has a distinctive feature, namely, relapse-remission or chronic active phase, so the discomfort that can occur in patients cannot be predicted. Ultimately, this can reduce patients' QoL.¹³⁻¹⁷ Thus, increased awareness among physicians and health workers is needed to improve health services for patients with IBD, as well as to maintain and assess their QoL from an early age.

Meanwhile, the IBDQ-9 has various benefits over other instruments, such as predicting fatigue in patients with IBD as an independent variable in multivariate analysis (odds ratio = 0.82; 95% CI = 0.74-0.93).¹⁴ Furthermore, the IBDQ-9 has a good correlation with IBD activity assessment in the UC activity index ($r = -0.530, p < 0.001$) and the CD activity index ($r = -0.424, p < 0.025$).¹⁵ Neubauer et al⁶ also described a good correlation between the IBDQ-9 and IBD disease activity, where the correlation in UC was better than in CD. The IBDQ-9 also has the same suitability for assessing HRQoL as the conventional instruments, the IBDQ-36 and SF-36.¹⁶⁻¹⁸ Therefore, the IBDQ-9 not only effectively assesses the QoL of patients but also serves as a predictor of fatigue and an evaluation parameter for IBD disease activity.

This was the pilot study in Indonesia to evaluate the IBDQ-9 instrument to quickly assess QoL that contains questions relevant to IBD characteristics.¹⁹ This measurement tool will be useful for the welfare of patients with IBD by improving the management approaches to some QoL aspects that may have been neglected.^{20,21} This study used many participants with various characteristics and was expected to represent

the general population, allowing this instrument to be applied to a broad population.⁵ A credible research location, namely Cipto Mangunkusumo Hospital, can increase the certainty of a definitive IBD diagnosis and prevent selection bias.

Nevertheless, this study had several limitations. Owing to time constraints and the cross-sectional design, the IBDQ-9 cannot be used to assess QoL in patients with IBD at various disease activity levels. Additionally, the IBDQ-9 had not been tested for validity and reliability in other populations, such as geriatrics.⁵ These limitations could affect the interpretation of the Indonesian version of the IBDQ-9 and should be considered in future research.

In conclusion, the IBDQ-9 Indonesian version was a valid and reliable tool for assessing the QoL of patients with IBD in Indonesia. The results of this study could be considered for the health sector stakeholders in making an algorithm for IBD examination and management, conducting early detection of QoL, identifying risk factors as a preventive measure for IBD complications in health services, disseminating the results of studies on the validity and reliability of the IBDQ-9 in patients with IBD as teaching materials in the field of gastroenterology to general practitioners and participants in internal medicine specialist education, and developing further research to obtain an overview of the comprehensive use of the IBDQ-9 Indonesian version, considering the study design and population variations.

Conflict of Interest

The authors affirm no conflict of interest in this study.

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