Quality of Life in Inflammatory Bowel Disease: Psychometric Evaluation of an IBDQ Cross-Culturally Adapted Version

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Abstract

Background & Aims. The health related quality of life (HR-QoL) construct was introduced as a requirement to assess the subjective health status. It is a multifaceted construct that has contributed to a better understanding of the patients' adaptation to his condition. The Inflammatory Bowel Disease Questionnaire (IBDQ), a widely used instrument to assess QoL among IBD patients, has already shown its validity and reliability. Our aim was to obtain an easier revised version of the (IBDQ-R) and to investigate its cross-cultural psychometric properties. **Method**. Carried out in a sample of outpatients recruited in a specialized University Clinic (n=76), this study began with the translation and linguistic validation of a self-report 32-item version of the questionnaire with a 7-point Likert type answering system. We assessed thereafter its reliability through internal consistencies and also looked into its discriminatory power. We also investigated its convergent validity with other health status - clinical assessment, SCDAI and CDAI-m - and well-being measures. **Results**. With a Cronbach's alpha = 0.92 for the global scale and a mean 0.82 for the subscales, internal consistencies proved adequate. On the other hand, discriminatory power was also significant according to the model. Moreover, the expected correlations between IBDQ and the clinical assessment, SCDAI, CDAI-m and perception of well-being support evidence of IBDQ-R's convergent validity. **Conclusion**. This IBDQ revised version is a highly promising instrument to easily, yet feasibly and comprehensively, assess the quality of life in inflammatory bowel disease; therefore its use in daily practice is worthy to be recommended.

Key words

Introduction

At a certain point a generalized conviction arose that the morbidity indexes commonly used to assess the outcome of health interventions were relatively poor in respect to the information they made available. This is what led to look for other means to assess the health status, namely the subjective health status, including the Quality of Life (QoL). This term is designed to cover the aspects essentially connected with medical care and health related experiences. A more precise description is given by the term health related QoL (HR-QoL), thus cleaning its multidimensional content from the exclusion of aspects unrelated with the aims of medical intervention [1].

But despite the abundant literature on the subject, one has to admit that its penetration in daily practice is still timid [2]. Indeed, the clinical body has kept some distrust towards adopting HR-QoL in its daily practice, to quantify the outcomes of its interventions, variables referred to human characteristics, side by side with lab data or endoscopic findings. Nevertheless, particularly when dealing with chronic conditions, one can assume as a primordial goal for the therapeutic intervention to somehow improve the patient's QoL; and this should be, in a final analysis, the touchstone to evaluate more effectively the outcomes of such intervention. What happens instead, to this purpose, is that the activity indexes in use, i.e. for inflammatory bowel disease (IBD), not only revealed themselves as little sensitive, but even conflicting with the patient's perception of his/her own status [3]. While on the opposite, these QoL indexes, in terms of clinical assessment of the disease activity, have been proved strongly related with better well-being and lesser use of health services [4].

In fact, in what concerns patients, more than the lab findings and physiologic reactions, the matter is about symptomatic complains and functional ability, where these

complains, assumed as of affective nature, are usually dismissed. Therefore it is important to assess the functional ability of the patients. That is, to screen patients with special needs, namely due to psychosocial difficulties, that these instruments may indicate or allow to localize. Simultaneously these allow to monitor clinical evolution, eventually suggesting alternative therapeutic approaches.

Nevertheless, although QoL, as compared to clinical assessment, is a better indicator of the health care consumption [4, 5], what happens is that this kind of information — be it by mistrust, inadequacy, or unavailability in the right moment - seldom is considered in decision making by health managers [6].

The simplest method of assessment consists in making a single question to the patient, who will integrate in his answer the various dimensions involved. However, herein also resides its hindrance; that is, evaluations of a single issue will not give us any information on the factors leading to this or that other answer.

On the generic instruments [7, 8], these are characterized by not taking into account specific aspects of the disease in question. Where the specific ones are designed to assess some states and worries inherent to the patients afflict by a particular disease. That will be the case of an instrument aimed at Crohn's Disease (CD), which will have to include issues related to intestinal functioning, abdominal pain, or of a sexual nature; where another one oriented towards rheumatoid arthritis may instead be interested in assessing hand strength and mobility. Advantages of this specificity reside in the added sensitivity to the clinical status variations that may occur along the evolution [9], hence a direct usefulness in clinical trials, but also the fact that the sort of questions and explored areas are very similar to those usually used by physicians for regular clinical assessment.

Conceived around its use in clinical trials, the Inflammatory Bowel Disease Questionnaire (IBDQ) [10-13] is a structured interview commonly used to assess HR-QoL. Translated into many different languages [14] - Dutch [15, 16], Portuguese [17-19], Spanish [20-22], Korean [23], UK English [24, 25], Greek [26, 27], Swedish [28, 29], Norwegian [30], Japanese [31, 32], German [33-35], Chinese [36], Lebanese [37], Brazilian [38] - it has shown its reliability, validity and cross-cultural stability.

The purpose of this study was to get an easy-to-use Portuguese version of the 32-item IBDQ and to investigate its cross-cultural psychometric properties.

Methods

Participants

The subjects for this study were recruited among patients being treated in an IBD specialized Clinic at the Gastroenterology Unit of a local University Hospital. Upon the hospital's Ethics Committee approval, and in accordance with the Helsinki Declaration, the study was conducted in a one year period, during which, on a weekly consultation, the patient with the first appointment scheduled was successively approached. All the 76 interviewed outpatients - 28 men and 48 women - after being properly informed, agreed upon free willing participation; thus providing written consent. All of them had their IBD diagnosed and classified by endoscopic and histological means according with ICD-10 [39].

Instruments

The study and its aims were introduced in a first moment of the interview. Then, following a structured form, socio-demographic data was collected by means of the Graffar index [40], as well as some relevant elements from the personal, familial and medical history.

Medical characterization

Inclusion criteria went through clinical classification after the radiologic, endoscopic and/or histopathological elements which allowed characterizing the location and extension. These were further consolidated with other objective data available from the patient's files.

Physician-reported global assessment

The accompanying specialized clinician was also asked to grade the disease activity on a five point scale, ranging from remission, mild and moderate, up to severe and very severe.

Survey Crohn's disease activity index (CDAI)

In order to characterize subgroups according to the disease activity, we also used the Survey CDAI [41], an index accurately placing patients into quartiles of disease severity equivalent to those produced by the CDAI [42].

Modified CDAI

Starting with the CDAI [42] another index has been put forth on a modified version (CDAI-m). In fact, except the hematocrit, the other variables required to calculate CDAI were available or else could be inferred after proper coding.

Taking into account that, as compared to clinical indicators, one can not conclude on the superiority of the biological parameters [43], the hematocrit was put aside from the start. The data actually collected about liquid or very soft stools referred to the last 24 hours, and not to the required 7 days of the week on a daily basis. Hence the deduction, to a certain extent, about the functional status along the last 7 days, ascertained taking the available number of stools of the last 24 hours as the daily average. Once the variables were weighted, instead of being kept as absolute numbers, a pre-coded value was adopted in the context of the formula for stools/week. The coding process was as follows:

[2 x (nr. of stools/week)] + [5 x (abdominal pain/week)] + [7 x (well-being/week)] + [20 x (extra-intestinal manifestations/week)] + [30 x (taking lomotil or opiates for diarrhea)] + [10 x (abdominal mass (0, 2, 5))] + [weight loss]

Although not equivalent to the CDAI, the resulting variable is an acceptable index to be used, side by side with others also here considered.

Patient-reported global assessment

Perception of well-being was quantified as proposed in

the Harvey-Bradshaw index [44], that is, the patient was asked, on a 0 to 4 scale — ranging from very well, good, fair, poor or very poor/terrible — how would he/she describe his general health status and well-being.

IBD questionnaire - revised (IBDQ-R)

Comprising 32 issues, besides a global score, the IBDQ covers bowel and systemic symptoms, as well as emotional status and social functioning. Well conceived, it has been repeatedly shown a psychometrically sound measure while replicable, stable and sensitive to variations among patients with IBD, outpatients as well as inpatients [10, 13-15, 24, 30, 45, 46].

In its original form, each question is followed by the enunciation in full of each and every possible alternative answer; 7 in all, one after the other. What, besides making it quite large, turns out to be hardly understandable by patients with an average education level, who have to successively memorize all the different options until reaching a decision on the final answer. This has been acknowledged from the start [46], in terms of validating the self-administration form [47] or of putting forward a shorter version scored in a 7-point scale [48].

In this revised 32-item version we addressed these issues proceeding to an adaptation of a self-report Likert style questionnaire. To achieve answering consistency along the questionnaire, in order to have a single header for the 32 items, we had to take into account the contents: affirmatively, or else negatively valued; and also the direct or reverse score of the respective item. This shortened it to two pages, important in the global context of the practicality of a time consuming evaluation requiring different instruments.

The questionnaire is administered to the patient with a brief explanation on the answering mode, mentioning that he/she should answer the questions thinking only in which extent those aspects have been present in the last two weeks.

Results

General characteristics

The ulcerative colitis (UC) subgroup consisted of 26 patients - 14 men and 12 women, with a mean age of 44.42 ± 12.64 years and a mean disease duration of 9.67 ± 7.59 years. Five patients with UC were asymptomatic, 6 had a mild disease activity, 7 had moderate activity, and 8 were in a more severe state.

The CD subgroup included 50 patients - 16 men and 34 women – with a mean age of 34.76 ±12.41 years and a mean disease duration of 10.15 ± 8.01 years. Eight patients with CD were in remission, 15 had a mild activity, 17 had moderate activity and 10 had severe activity.

Besides patients with UC being older than those with CD (p = 0.002), there were no significant differences between the two subgroups concerning the mean Graffar index. This was 15.51 ± 3.45/25 for the whole sample, with a statistical mode of 3/5 - corresponding to a socioeconomic class III in the Hollingshead index. There were no significant differences

regarding the duration of the disease, but significant regarding the age of onset, which was younger for CD (24.80 ± 11.00) than for UC patients (34.77 ±12.79) (p = 0.001).

The IBD activity was at level 1 (quiescent) in 13 patients, at level 2 (mild) in 21 patients, at level 3 (moderate) in 24 patients, and at level 4 (severe) in the other 18. The ratio between patients with asymptomatic/mild activity (UC = 42.3%, CD = 46.0%) and those with severe symptoms (UC = 57.7%, CD = 54.0%) was not significantly different.

Most of the patients were treated with 5-aminosalicylate - 90% of the CD patients and 92.3% of those with UC, as well as, according with the disease's activity, with corticosteroids: 48% of the CD patients and 26.92% of those with UC. It is noteworthy that 36% of the CD patients and 42% of those

Table I. IBDQ-R - Portuguese version

Reliability of the scales

IBDQ-R (N = 76)		Item-Total Correlation	Rmult^2	Cronbach's α If excluded
Global score α = 0.92				
Bowel symptoms α= 0.84	BS-01	0.45	0.27	0.83
	BS-05	0.39	0.35	0.84
	BS-09	0.68	0.75	0.81
	BS-13	0.79	0.82	0.80
	BS-17	0.50	0.31	0.83
	BS-20	0.62	0.48	0.82
	BS-22	0.49	0.31	0.83
	BS-24	0.65	0.49	0.81
	BS-26	0.41	0.31	0.84
	BS-29	0.38	0.35	0.84
Systemic symptoms α= 0.77	SS-02	0.63	0.45	0.70
	SS-06	0.56	0.36	0.72
	SS-10	0.63	0.45	0.69
	SS-14	0.45	0.22	0.76
	SS-18	0.47	0.23	0.76
Emotional status α= 0.87	ES-03	0.65	0.69	0.86
	ES-07	0.32	0.39	0.88
	ES-11	0.62	0.49	0.86
	ES-15	0.70	0.50	0.85
	ES-19	0.57	0.48	0.86
	ES-21	0.62	0.56	0.86
	ES-23	0.42	0.32	0.87
	ES-25	0.74	0.62	0.85
	ES-27	0.56	0.52	0.86
	ES-30	0.69	0.64	0.86
	ES-31	0.53	0.41	0.86
	ES-32	0.42	0.36	0.87
Social functioning α= 0.87	SF-04	0.59	0.39	0.78
	SF-08	0.64	0.41	0.76
	SF-12	0.63	0.42	0.77
	SF-16	0.53	0.39	0.80
	SF-28	0.64	0.45	0.77

with UC also received psychopharmacological drugs, mainly patients with simultaneous prescription of corticoids.

Reliability (Table I)

Internal consistencies, evaluated by means of the Cronbach's coefficient alpha [49], were reasonably high: the overall questionnaire equals 0.92 and the subscales a mean 0.82. Multiple regressions item-scale - correlation between each item and the sum of all others in the scale - goes also in the same sense, leaving as marginal the contribution of item 7 for the emotional status.

The same consistency was found for CD and UC when item analysis was performed independently for both groups. Namely with a 0.97 Cronbach's alpha for the global score and a mean 0.82 for the subscales, in the case of CD; and in the case of UC, with a Cronbach's alpha equal to 0.96 for the global score and a mean of 0.83 for the subscales.

Discriminatory ability (Table II)

To crudely assess its responsiveness, we tested the instrument's ability to discriminate patients according to disease activity as assessed by the SCDAI and categorizing them into quartiles. Then the lower quartile subgroup - clinical remission to mild activity - was compared with the higher quartile one — moderate to severe activity. We observed that the IBDQ-R global score, as well as its subscales', was significantly lower (p = 0.000) among patients with a less controlled illness.

Construct convergent validity (Table III)

As it may be seen by Pearson r, IBDQ-R scores were also significantly lower (i.e. poor QoL), the worst the health status as assessed by other objective means: SCDAI (r = - 0.62; p = 0.000) and CDAI-m (r = - 0.62; p = 0.000). They were significantly related, as expected, with a poor perception of well-being (r = - 0.53; p = 0.000). The same significant relationships were reproducible both in CD and UC.

Discussion

In general terms, the here analyzed instrument to specifically assess QoL in IBD has content value: its questions effectively represent the aspects meant to be explored. This refers to the scale construct validity, seeing that, built about a hypothesized model of health status, it was tested in patients previously characterized by their specificity, thus confirming the model. But it also refers to

Table II. IBDQ-R - Portuguese version (n=76)

Discriminatory ability according to SCDAI

	Lower Quartile (N = 19)	Higher Quartile (N = 19)	Student's t	p
IBDQ-R Global score	176.58 ± 34.11	118.42 ± 25.63	5.94	0.000
Bowel Symptoms	58.63 ± 10.51	40.00 ± 8.96	5.88	0.000
Systemic Symptoms	23.53 ± 6.96	15.37 ± 4.92	4.17	0.000
Emotional Status	65.32 ± 12.70	42.11 ± 9.32	6.42	0.000
Social Functioning	29.11 ± 6.93	20.95 ± 7.76	3.42	0.000
General well-being	0.00 ± 0.00	2.00 ± 0.94	- 9.25	0.000
Clinical Assessment	0.21 ± 0.42	1.79 ± 1.03	- 6.18	0.000
SCDAI	29.84 ± 10.02	333.58 ± 77.74	- 16.89	0.000

the concurrent validity, since the respective scores, although not fully overlapping, correlate with those in other previously used instruments that were also meant to assess some of the aspects involved in general well-being: patient report, physician global assessment, survey CDAI and modified CDAI.

The item analysis revealed in turn that the instrument is rather homogeneous in its dimensions. In fact, the internal consistency as assessed by the Cronbach's alpha, as well as by the item-total correlations, indicate just that.

Based on our data one can discuss the scale's sensitivity, since its discriminatory power allows us to conclude about its usefulness to record changes as the clinical condition changes. Nevertheless, although promising, its usefulness should be further explored in samples specifically collected among in-patients, as well as out-patients, in order to definitely establish its behavior in relation to the 'ceiling' and 'floor' effects. And since this study adopted a cross-sectional approach, further prospective research is also required in order to effectively establish its predictive power.

Due to the particular type of target population under scrutiny, which refers to diseases relatively uncommon

Table III. IBDQ-R - Portuguese version (Pearson r correlations)

Convergent validity (N = 76)

	Clinical assessment		SCDAI		CDAI-m		General W-B	
	r	p	r	p	r	p	r	p
IBDQ-R Total	- 048	0.000	- 0.62	0.000	- 0.62	0.000	- 0.53	0.000
Bowel symptoms	- 0.46	0.000	- 0.63	0.000	- 0.61	0.000	- 0.43	0.000
Systemic symptom	- 0.50	0.000	- 0.55	0.000	- 0.57	0.000	- 0.51	0.000
Emotional status	- 0.40	0.000	- 0.60	0.000	- 0.59	0.000	- 0.55	0.000
Social functioning	- 0.41	0.000	- 0.38	0.001	- 0.40	0.000	- 0.38	0.001

SCDAI: Survey Crohn's activity index; CDAI-m: Crohn's activity index modified; W-B: well-being

- IBD prevalence from US estimate around 89.6-103.0 per 100,000 persons for CD and 146.6-164.9 per 100,000 person for UC - we had to prolong data collection in the field for a 1 - year long period. This was a limitation, since the size of the collected sample, although proven adequate for the analysis performed in this study, did not have enough power to allow us to further analyze the internal structure of the questionnaire by means of Factorial Analysis. Nevertheless, although open to further Confirmatory Analyses, the present figures, namely on internal consistencies, are rather suggestive by themselves.

The IBDQ is a rather informative tool, comprising four factors, besides a global score on subjective health status: namely covering bowel and systemic symptoms, as well as the emotional status and social functioning.

In **conclusion**, we consider that this IBDQ revised version is a feasible instrument that comprehensively assesses QOL among IBD patients. Given the fact that CD and UC are chronic debilitating diseases with an important adverse impact on patients' lives, and bearing in mind that, together with a rather straightforward scoring system, its size - 32 issues in a single sheet (two pages) layout - and the fact that it can be self-administered, make the task of collecting data a very easy and fast one, the use of IBDQ revised version should be recommended for research - epidemiological, clinical trials, etc. - as well as for daily practice.

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Conflicts of interest

None to declare.

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