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Quality of Health Care in Inflammatory Bowel Disease: Development of a Reliable Questionnaire (QUOTE-IBD) and First Results

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ABSTRACT

OBJECTIVES: As inflammatory bowel disease is a chronic disorder, usually with an early onset in life, quality of care plays an important role for patients. The aim of this study was to develop a questionnaire to measure quality of care through the eyes of patients with inflammatory bowel disease .

METHODS: Ten generic questions were already available because the questionnaire is based on an existing instrument . Patients with inflammatory bowel disease in seven countries were involved in the development of additional disease-specific items. Validation and first field testing of the total questionnaire (QUOTE-IBD) was performed in The Netherlands .

RESULTS: A total of 380 patients cooperated in the development of 13 disease-specific items, with high internal reliability (Cronbach's _ _ 0.83). Another 162 patients were involved in validating and testing of the QUOTE-IBD, which consists of 23 items in total. Pearson's correlation coefficient between QUOTE-IBD and visual analog scale scores of health care items was 0.55. Intraclass correlation coefficient of two assessments was 0.64. First testing showed that patients gave relatively poor marks to some part of health care services, such as providing information about extraintestinal complaints and the psychological as well as physical approach to complaints

\CONCLUSIONS: A short, valid, reliable questionnaire was developed to measure the opinions of patients with inflammatory bowel disease on quality of health care. The QUOTE-IBD can be used for identification of areas for improvement, with the aim of optimizing health care in inflammatory bowel disease. (Am J Gastroenterol 2001;96: 3329–3336. © 2001 by Am. Coll. of Gastroenterology)

INTRODUCTION

Inflammatory bowel disease (IBD) comprises several disease entities, the most common being ulcerative colitis and Crohn's disease. Because IBD is a chronic continuous or recurrent disorder, health care plays an important role in the life of this patient group. The early onset, chronic nature, and sometimes intensive course of IBD can result in a considerable need for health care. Frequently exacerbations have to be treated with the patient admitted to the hospital. To monitor medication, regular outpatient visits are required (1, 2). Therefore, in addition to medical and surgical therapy, health care workers should focus on a high standard of the care provided. Generally, health care is worth studying as a dependent variable, but also as a predictor variable for e.g., compliance to therapy, quality of life, and health status. In IBD, until today some selected aspects of quality of care have been studied, e.g., regarding patient information (3-5). However, so far no study has been conducted to assess the total concept of quality of care in this group of disorders. During the last decade, increasing attention has been paid to measuring quality of health care. The health care provider's perspective, which is reflected in most of the existing instruments for measuring quality of health care, differs substantially from that of the user of health care facilities—namely, the patient (6). To our knowledge, no instrument exists for measuring the IBD patient's perspective on the health care provided . The aim of the present study was to develop a questionnaire that represents the opinion of IBD patients on the quality of health care provided, to be used in national or international comparisons. Therefore, patients in seven countries were involved in the development. To evaluate whether the questionnaire achieved its purpose we admin- istered it to a group of IBD patients who have experienced the disease for many years.

MATERIALS AND METHODS

Patients

In the present study, participants in the development of this questionnaire that measures quality of care from the patient's perspective were IBD patients from six European countries (Norway, Ireland, The Netherlands, Portugal, Italy, Greece) and Israel. All patients were randomly selected from registration files in the participating hospitals. They were asked to indicate on a short questionnaire which specific care aspects they considered as being important. The structuring for similarity and importance of the items mentioned, the reduction of the number of items, and the validation of the questionnaire were conducted in The Netherlands and involved only Dutch patients. The treating physicians of all patients gave permission to approach their patients for this study. Centers in the above-mentioned countries participate in a study on quality of health care in IBD in the context of the European Collaborative Study Group on Inflammatory Bowel Disease (EC-IBD) (7). Where needed, the Medical Ethics Committees of the centers involved gave their approval for this study. IBD was uniformly defined by using the classification criteria of Lennard-Jones, used in a large previous survey of IBD by the same working group (8–10).

Methods

The Netherlands Institute for Health Services Research (NIVEL) has developed a series of questionnaires that measure Quality of Care Through the Patient's Eyes (QUOTE) and can be completed anonymously by patients (11). The QUOTE instruments are developed particularly for chronically ill patients, elderly persons, disabled persons, and individuals who use specific health care services. They address health care provided by general practitioners, specialists, or other services as applicable. In the QUOTE instruments, Donabedian's "structure-process-outcome" characterization of quality of health care is incorporated (12). This model defines "structure" as characteristics of the health care system, whereas "process" addresses the encounter between a physician or another health care

professional and a patient (13–15). "Outcome" refers to the patient's subsequent health status, which is the end result of care (e.g., quality of life). It is incorporated in the QUOTE instruments when this is suggested by patients, which is rarely the case in chronic diseases. In the QUOTE instruments, three features are explored: 1) the weight that patients give to various care aspects ("importance"); 2) the experiences concerning the functioning of medical practices and health care workers for each aspect of care ("performance"); and 3) the combined effect of importance and performance ("quality impact"). The scoring system is explained in the Appendix . The QUOTE instruments consist of both generic and diseasespecific questions concerning health care provided during the past year. The NIVEL has developed 10 generic questions that are similar for all QUOTE questionnaires for various patient groups (16–18). The focus of the present study was to develop disease-specific questions of a QUOTE instrument for IBD patients and to test the complete instrument in a realistic situation. In the following discussion, the resulting questionnaire will be referred to as the "QUOTE-IBD," including the 10 generic questions. The health care providers that are predominantly involved in the treatment of IBD are specialists and general practitioners. Therefore, the questions in the QUOTE-IBD address these two professional categories by repeating all questions for either of them. When developing a questionnaire to assess quality of care from the patient's perspective, it is essential to involve patients (19). For this purpose in the present study we used "concept mapping," a structured, participant-orientated process (20). This process allows all participants (patients) to have an equal say in the final assessment (questionnaire). It is a so-called "bottom-up" process, as it starts with multiple specific ideas derived from brainstorming before it moves to more general concepts. In this procedure, patients are involved during three stages: 1) to generate a list of relevant care aspects; 2) to structure these aspects for similarity and importance; and 3) to reduce the number of aspects to be included in the questionnaire.

Validity and Reproducibility of QUOTE-IBD

To guarantee correct measurement of the concept (quality of health care from the patient's point of view), construct and content validity were measured for the QUOTE-IBD. Because no gold standard is available to determine construct validity, i.e., the degree to which an instrument measures the theoretical construct it is intended to measure (21), in this study visual analog scales (VAS) were used as proxy measures to assess the patient's opinion of the care provided, both as a total and as separate care dimensions. The VAS consisted of horizontal lines with a statement at both ends, in which the left side represented the worst and the right side the best possible experience. Scores were calculated as percentages of the scale, with 0% indicating the worst experience and 100% indicating the best experience with the health care provided. However, for two dimensions ("autonomy" and "costs"), no VAS were included, as they contributed one single question each to the OUOTE-IBD. To investigate content validity with regard to the QUOTE-IBD, the patients were asked to indicate which other aspects of care should be included to give a more complete representation of health care in IBD. The reproducibility of the QUOTE-IBD was determined by asking participants to complete the QUOTE-IBD twice, at an interval of 4 wk. They were also asked to mark their experience with the provided care on the VAS scales both initially and at follow-up.

[TABLE 1]

Applicability of the QUOTE-IBD

Because it has been stated that, in general, 90% of a population are satisfied with the quality of care provided, we decided to use this information for our QUOTE-IBD (13). When 90% of the population give a good evaluation (and, thus, 10% give a poor evaluation) of a particular aspect or dimension of care, the corresponding performance score in the population for this aspect will be 0.1. This score combined with extreme importance (score _ 10) of the aspect leads to a quality impact score of 9.0 (quality impact _ 10 _ [importance _ performance]). An average quality impact score _9.0 indicates that more than the usual 10%

of the population give a poor evaluation of the certain care aspect; in other words, there is room for improvement concerning that particular item .

Statistical Analysis

Statistical analyses were performed with the SPSS package, version 8.0 for Windows (SPSS, Chicago, IL). Identification of the optimal set of aspects describing the quality of care in IBD was conducted using principal component factor analysis . Items with factor loadings _0.5 were preserved. Internal reliability of the questionnaire was evaluated by means of testing internal consistency, expressed as Cronbach's _. Mann-Whitney tests were performed to investigate differences in importance, performance, and quality impact scores for patients with Crohn's disease versus ulcerative colitis and for men versus women. Pearson's correlation coefficients between VAS and quality impact scores, and between VAS and performance scores of the QUOTE-IBD, were calculated for each dimension and for the total care received. Reproducibility of the QUOTE-IBD was determined by calculating Pearson's correlation coefficient between quality impact as well as performance scores of the two assessments. Cohen's _ (intraclass correlation coefficient) was calculated for quality impact and performance scores to examine the degree of agreement between the two assessments .

RESULTS

The process of development and testing of an instrument concerning quality of health care and characteristics of all patients involved is represented in Table 1.

Concept Mapping

A total of 267 European (107 Norwegian, 30 Irish, 47 Dutch, 24 Portuguese, and 59 Italian) and 19 Israeli IBD patients indicated 54 different aspects of care that they considered of the highest importance for good quality of care . In all participating countries, similar aspects were mentioned; however, aspects concerning cost and hygiene seemed to be mentioned more in southern than in northern countries . Of 53 Dutch IBD patients who were invited to sort the aspects for similarity, 30 patients responded positively (57% response rate). Cluster analysis assigned all aspects to eight generally accepted dimensions of care found in the literature (13–15). One-factor analysis of importance ratings of the 54 IBDspecific aspects resulted in 21 aspects with factor loadings _0.5. These 21 aspects were sent to a separate group of 97 Dutch IBD patients to reduce further the number of diseasespecific items. Again, the patients were asked to rate the aspects for importance. A total of 64 patients (66%) responded to our request. The data were subjected to explorative factor analysis, using principal component analysis. Of 21 items, 12 items finally received factor loadings _0.5.

[TABLE 2]

Inclusion of Care Aspects in the Questionnaire

Eventually, three other disease-specific aspects were included in the questionnaire despite exclusion according to principal component analysis. Reasons for inclusion were: 1) highest total importance score (item 21: In case of acute problems a doctor should be available within 24 h); 2) particularly mentioned during the concept mapping procedure in countries other than The Netherlands (item 17: Hospitals and medical practice rooms should have good toilet facilities); and 3) the investigators themselves placed high value on the IBD-specific item (item 16: Nurses at the endoscopy department should have specific expertise in IBD) . On the other hand, two aspects with factor loadings _0.5 in principal component analysis were excluded from the final questionnaire. One was excluded because a very low correlation was observed with other items in the dimension, and the other was excluded because a similar generic item was already available. Cronbach's _ of the remaining 13 IBD-specific aspects was 0.83. Table 2 shows all items included in the QUOTE-IBD .

[TABLE 3]

Validation of the Dutch QUOTE-IBD

For validation of the QUOTE-IBD, a group of 231 Dutch IBD patients outside the EC-IBD cohort were sent the questionnaire. Of those approached, 162 patients completed the QUOTE-IBD and the included VAS scales (70% response rate). Mann-Whitney tests did not show any differences in importance, performance, and quality impact scores for patients with Crohn's disease versus ulcerative colitis . Between men and women, differences were observed for several scores regarding quality impact, importance, and performance (Table 3) . Pearson's correlation coefficients were calculated for performance as well as quality impact scores. As illustrated in Table 4, correlations between the VAS and the total QUOTE-IBD performance and quality impact scores were 0.56 and 0.55, respectively . No new aspects to be included in the QUOTE-IBD were suggested by this group of patients .

Reproducibility

Of 162 patients approached, 148 patients agreed to a test– retest assessment. Data from 118 patients (80% response rate) were used for statistical analysis, as they had indicated that the time between the two assessments had been stable and that no specific event had occurred concerning the health care provided. Pearson's correlation coefficients between the two assessments are shown in Table 5, resulting in coefficients for total performance and quality impact scores of 0.80 and 0.76, respectively. Intraclass correlation coefficients for total performance and quality impact scores were 0.63 and 0.64, respectively.

Applicability

[TABLE 4]

As the number of patients who had consulted a general practitioner during the previous year was too small, only the data for the specialist are shown here . In Table 2 the importance, performance, and quality impact scores of the 162 Dutch IBD patients who participated in the validation of the QUOTE-IBD are presented for each question. The average group quality impact scores of "waiting time in waiting room," "psychological approach," "information about extraintestinal complaints," "information about nutrition," and "attention to IBD and family/work" were _9.0. The total and dimensional quality impact scores of the entire patient group and the differences between male and female patients are presented in Figure 1. In this figure, a line delimits a quality impact score of 9.0. Quality impact scores for the total group were below this level for the dimensions "competence" and "information." In addition, women scored "courtesy" _9.0 .

DISCUSSION

IBD is a relatively common, chronic, benign inflammatory disease that mostly affects young persons (22). Mortality rates are similar to those of the background population 23–26). The disease can have many medical and, in particular, social consequences, and is therefore an excellent example to show that well-organized health care can give good results. To study the hypothesis that quality of health care influences quality of life of IBD patients, for quality of life (QoL) a valid questionnaire (e.g., the IBDQ) exists, whereas for the assessment of the quality of care (QoC) no evaluated instrument has been available (27). In this study we have developed a valid, reliable questionnaire to assess quality of care through the patient's eyes QUOTE-IBD). This was conducted in a multinational set-ting in cooperation with a large number of IBD patients. The result is an instrument that is easy to complete, anonymous, and self-administered—all of which are important features to prevent the bias that could be expected when patients are interviewed by representatives of a hospital or other medical organization. The questionnaire covers the health care provided in the past year, as it has been shown that patients (especially those with complicated conditions) do not describe their experiences in terms of single visits but, rather, in terms of periods of disease

and/or care (28). The QUOTE-IBD consists of 10 generic and 13 IBD specific items, and combines both importance and performance evaluations. The 23 items are in agreement with the literature, inasmuch as eight generally accepted dimensions of care (accessibility, costs, accommodation, continuity of care, courtesy, information, competence, and autonomy) are represented by at least one item in our concept (13–15). The 10 generic questions included in the QUOTE-IBD also constitute part of similar QUOTE instruments for other chronic illnesses such as rheumatic disease and chronic obstructive pulmonary disease, and can therefore serve as material for comparison between different diseases (17, 18). One might expect that the disease-specific items would hold more "process of care" aspects, such as frequency of monitoring and adequate symptomatic therapy; however, those items were not mentioned frequently or given much importance by the patients. Therefore, the current items in the QUOTE-IBD should be considered to give a correct representation of the patient's perspective on quality of health care. As is shown in detail in this study, measurement of the construct validity of the QUOTE-IBD using proxy measures was good. The observed correlation coefficients between VAS and QUOTE-IBD scores were moderately high, except in three dimensions (i.e., competence, accommodation, and continuity of care). Reasons for this could be the following: 1) because the QUOTE-IBD is a newly developed questionnaire, based on a new conceptual theory (i.e., quality of care from the patient's opinion, in which importance is incorporated in addition to satisfaction), no gold standard or even a comparable instrument is available that would be optimal for validation; 2) some patients seemed to find it difficult to use the VAS scales; 3) the QUOTE-IBD specifies a number of events whereas the VAS scales ask for general evaluations. Despite these limitations, the results raise positive expectations concerning the construct validity of the QUOTE-IBD in Dutch patients. In addition, according to the patients, the items included in the questionnaire completely represented their ideas of health care in IBD. This indicates that the content of the questionnaire is valid in The Netherlands. Further validation of the QUOTE-IBD in other countries is required. The QUOTE-IBD has proved likely to reproduce similar results at an interval of 4 wk. Pearson's correlation coefficients between the two assessments of performance and quality impact scores were high (29). Intraclass correlation coefficients can be considered moderately high, except for the quality impact score of "continuity of care" and the performance scores for "accessibility," "accommodation," and "continuity of care" (21). This may be explained by the fact that the median duration of disease of the patients who completed the questionnaire was 12 yr. It is likely that most of these patients are in stable condition and, therefore, had only little or no experience with these particular care aspects during the past 1 yr. On these grounds, and taking the high internal consistency of the IBD-specific questions into consideration, the QUOTE-IBD can be regarded as a reliable measure. It might be seen as a disadvantage that the OUOTE-IBD has been developed in a multinational setting and thus does not provide specificity for each country. On the other hand, this can be regarded as an advantage because it creates the possibility of international comparisons. Although applicability of the QUOTE-IBD was tested in a limited number of patients in any one nation, some very informative results already emerged. First, it is not necessary to distinguish between Crohn's disease and ulcerative colitis when assessing the patient's view on the quality of the provided health care, as statistical analyses did not show differences between these disease entities in QUOTE-IBD scores. Second, female patients seemed to give poorer evaluations of the provided care than did male patients, as reflected by significantly lower quality impact scores for competence, courtesy, and information. The literature reports inconsistent findings regarding male and female patients' views on quality of health care (30–32). This inconsistency might be due to the use of different instruments for data assessment; however, the possibility of a real difference between men and women should not be neglected. Until these issues are better understood, no gender-specific recommendations for the organization of health care can be made. Furthermore, during this first use of the QUOTE-IBD we were able to identify health care areas that might need improvement, both on the level of individual care items (e.g., information about nutrition)

and of dimensions of care (e.g., competence). These preliminary results have encouraged us to use the QUOTE-IBD on a large scale in an ongoing EC-IBD study in 1177 patients concerning the influence of quality of care on quality of life (33) . In conclusion, assessing IBD patients' experiences with health care has resulted in a short, self-administered instrument that was shown to be valid and reliable. The QUOTEIBD seems to be easy to use when studying quality of health care for patients with IBD, and it can enable researchers to identify targets for improvement both in hospital settings and in general practice. When arrangements have been made to improve a certain aspect of health care, the QUOTE-IBD measurement should be repeated to confirm whether the improvement has taken place. As good quality of care seems to be essential in chronic diseases, the QUOTE-IBD should become an important tool in addition to traditional methods to optimize health care for IBD patients .

[TABLE 5]

[FIGURE 1]

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[APPENDIX 1]

TABLES, FIGURES AND APPENDIX

Table 1. Development of QUOTE-IBD and Patient Characteristics

		Patien	t Characteristics	_
Procedural Steps	No. of Patients	No. of Men	Median Age (yr)	Mean Duration of Disease (yr)
Item selection Survey of 286 IBD patients in seven countries to identify IBD-specific items	134 UC 152 CD 286 IBD	58 69	40 39	9.1 7.3
Involvement of 30 Dutch IBD patients to structure 54 items for similarity and importance	18 UC 12 CD 30 IBD	7	51 51	7.8 15.3
Construction of Item Reduction Questionnaire Item reduction Questionnaire administered to 64 Dutch IBD patients	39 UC 25 CD 64 IBD	22 11	41 41	4.1 2.8
13 items included in QUOTE-IBD after principal component analysis and internal consistency analysis Testing of QUOTE-IBD in Dutch patients with 10 generic and 13 IBD-specific items Validity testing	69 UC 93 CD 162 IBD	33 30	48 45	12.0 12.0
Reproducibility testing	56 UC <u>62 CD</u> 118 IBD	28 18	47 46	13.0 12.0

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Table 2. Items Included in QUOTE-IBD, and Importance (I), Performance (P), and Quality Impact (QI = 10-[I*P]) Scores of 162 Dutch IBD Patients Per Item

	Importance Score	Performance Score	Quality Impact Score
Generic: Doctors, nurses and other health care workers			
(CM) 1 should have a good understanding of the patient's problems	7.48	0.07	9.48
(AU) 2 should allow the patient to have input in decisions regarding	7.65	0.12	9.08
treatment received			
(CO) 3 should take the patient seriously	8.47	0.07	9.41
(CO) 4 should keep appointments punctually	6.29	0.06	9.62
(A) 5 should not keep the patient in the waiting room for more than 15 minutes	3.88	0.32	8.76*
(I) 6 should inform the patient about medicines that are prescribed	7.76	0.10	9.22
(C) 7 should prescribe medicines which are fully covered by insurance	5.62	0.02	9.89
(A) 8 should be easy to reach by telephone	6.22	0.09	9.44
(CC) 9 should make sure that the patient can consult a(nother) specialist	7.31	0.08	9.66
within 2 weeks after referral			
(CC) 10 should communicate with other health care workers about	5.92	0.08	9.53
required services			
IBD-specific			
(AC) 11 Waiting areas and consulting rooms should be clean and orderly	6.25	0.01	9.94
(CM) 12 Doctors and nurses should also approach my physical complaints	6.49	0.31	7.99*
from a psychological point of view			
 (I) 13 Doctors and nurses should inform me clearly about the examinations 	8.11	0.03	9.76
I am subjected to			
(CC) 14 I should usually be seen by the same doctor	6.85	0.01	9.93
 (I) 15 Doctors should inform me clearly about other possible physical 	8.26	0.35	7.11*
problems due to IBD, e.g., joint pain			
(CM) 16 Nurses at the endoscopy department should have specific expertise in	8.10	0.02	9.84
IBD			
(AC) 17 Hospitals and medical practice rooms should have good toilet	7.28	0.08	9.42
facilities			
(A) 18 If my doctor is absent an adequately competent substitute should be	7.58	0.04	9.70
available	6.50	0.22	7.00*
(I) 19 In health institutions adequate information about nutrition and IBD	6.58	0.32	7.89*
should be available to me	6.01	0.01	0.02
(CC) 20 It should be possible for me to consult my doctor regularly	6.81	0.01	9.93
(A) 21 In case of acute problems a doctor should be available within 24	9.05	0.07	9.37
hours	5 77	0.49	7.02*
(CO) 22 Doctors and nurses should pay attention to the influence of my IBD	5.77	0.48	7.23*
on my family life and/or work situation	7.60	0.06	9.54
(CO) 23 As an IBD patient I should have confidence in my doctor	7.00	0.00	9.34

The QUOTE-IBD consists of 10 generic and 13 IBD-specific questions, which must be rated for importance and performance. The question style is different for generic and IBD-specific questions. The wording deliberately is repetitious, as it has been reported that repetition ensures subjects' understanding. The questions belong to eight categories: accessibility (A), costs (C), accommodation (AC), continuity of care (CC), courtesy (CO), information (I), competence (CM), and autonomy (AU). Response options are consistently presented as four-point scales (see Materials and Methods).

* Score < 9.0.

Table 3. Total and Dimensional Importance, Performance, and Quality Impact Scores for 162 Dutch Male and Female IBD Patients

	I (m)	I (f)	P (m)	P (f)	QI (m)	QI (f)
Total care	6.82	7.05	0.09	0.15*	9.51	9.04*
Competence	6.88	7.05	0.11	0.25*	9.44	8.41*
Courtesy	6.92	7.14	0.13	0.18	9.31	8.84
Accessibility	6.78	6.64	0.10	0.16	9.45	9.25
Information	7.34	7.87*	0.15	0.23	9.03	8.22*
Continuity of care	6.51	6.82	0.01	0.06*	9.94	9.66
Accommodation	6.58	6.88	0.02	0.06	9.82	9.52
Autonomy	7.34	7.73	0.07	0.15	9.75	9.04
Costs	5.51	5.72	0.03	0.01	9.81	9.94

f = female; I = importance, ranging from 0 (least important) to 10 (most important); m = male; P = performance, ranging from 0 (best performance) to 1 (poor performance); QI = quality impact, ranging from 0 (poor) to 10 (best).

p < 0.05.

Table 4. Construct Validity of QUOTE-IBD: Correlation Coefficients Between Total Score as well as Dimensional Scores of QUOTE-IBD and Visual Analog Scales for Quality Impact and Performance Scores in 162 Dutch IBD Patients

Care Dimension	Quality Impact	Performance
Total care	0.55*	0.56*
Information	0.55*	0.60*
Courtesy	0.56*	0.60*
Competence	0.31*	0.40*
Accessibility	0.51*	0.57*
Accommodation	0.23†	0.47*
Continuity of care	0.28†	0.36*

< 0.001.

Table 5. Reproducibility of QUOTE-IBD: Agreement Between Two Sets of Measurements, Expressed by Correlation Coefficients and Intraclass Correlation Coefficients Between Quality Impact and Performance Scores for Total and Dimensional Scores of QUOTE-IBD in 118 Dutch IBD Patients

QUOTE-IBD	R	ICC	R	ICC
Dimensions	Quality Impact	Quality Impact	Performance	Performance
Total care	0.76*	0.64*	0.80*	0.63*
Information	0.70*	0.58*	0.81*	0.50*
Courtesy	0.66*	0.53*	0.76*	0.56*
Competence	0.56*	0.42*	0.71*	0.67*
Accessibility	0.60*	0.57*	0.57*	0.32†
Accommodation	0.59*	0.47*	0.53*	0.23†
Continuity of care	0.33†	0.26†	0.39*	0.26†
Autonomy	0.50*	0.59*	0.69*	0.60*
Costs	0.86*	0.66*	0.43*	0.66*

ICC = intraclass correlation coefficient; R = correlation coefficient.

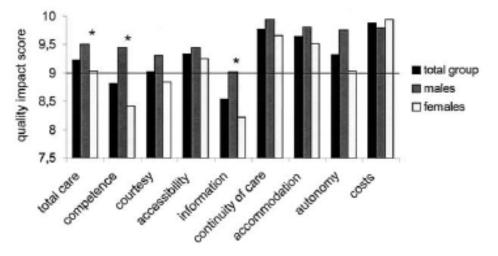


Figure 1. Total care score and dimensional Quality Impact scores for the total group (n = 162) and male (n = 63) and female (n =99) Dutch patients. p < 0.05 for difference between male and female patients.

 $[\]dagger p < 0.01$.

p < 0.001.

 $[\]dagger p < 0.01$.

APPENDIX

Scoring System of the QUOTE-IBD

With regard to the *importance* part of the QUOTE-instruments, responses to the statements mentioned are graded on a four-point Likert scale, in which 0 = "not important"; 3 = "fairly important"; 6 = "important"; and 10 = "extremely important." Population importance scores range between 0 and 10.

Example
Doctors and nurses should inform me clearly about the examinations I am subjected to.
□ Not important (answer represents 0)
☐ Fairly important (answer represents 3)
☐ Important (answer represents 6)
☐ Extremely important (answer represents 10)
Performance responses to the same statements are scored on a four-point scale as well: 1 = "no" or "not really"; and 0
"on the whole, yes" or "yes." Average population performance scores range between 0 and 1.
Example
The specialist I have seen during the past year has informed me adequately about the examinations I am subjected to.
□ No (answer represents 1)
□ Not really (answer represents 1)
☐ On the whole, yes (answer represents 0)
☐ Yes (answer represents 0)

Example

When a patient rates a certain aspect as extremely important and has had a good experience with the performance of this aspect, the individual quality impact score will be: $10 - (10 \times 0) = 10$.

as follows: Quality Impact = 10 - (Importance × Performance) (see Ref. 12).

Quality impact scores of patients concerning a health care aspect can be derived from importance and performance scores

When a patient rates another aspect as fairly important, but has no good experience, the score will be: $10 - (3 \times 1) = 7$. Average quality impact (QI) scores range from 0 (worst) to 10 (best).