

Quality of care in an inflammatory bowel disease clinical trial center : a prospective study evaluating patients' satisfaction

S. Coenen^{1,2}, M. Haeck¹, M. Ferrante^{1,2}, M. Noman¹, G. Van Assche^{1,2}, S. Vermeire^{1,2}

(1) Department of Gastroenterology and Hepatology, University Hospitals Leuven, KU Leuven, Leuven, Belgium ; (2) Translational Research Center for Gastrointestinal Disorders (TARGID), Department of Clinical and Experimental Medicine, KU Leuven, Leuven, Belgium.

Abstract

Background & study aims : Quality of care is a very timely topic in medicine. We designed a questionnaire to measure perceived quality of care and to explore areas of improvement.

Patients & methods : In this prospective study a questionnaire was developed and administered to all patients with inflammatory bowel disease participating in a randomized clinical trial. The questionnaire was based on validated surveys and supplemented with novel, relevant questions. Factors associated with (poor) quality of care were identified.

Results : Between October 2016 and January 2017, all 107 patients participating in a randomized controlled trial completed the questionnaire (63% male, 76% ulcerative colitis, median age of 47 years). The median satisfaction score was 9 out of 10. Areas of improvement were that too little attention was paid to the disease impact on family and work, dietary and exercise pattern, daily activities and quality of life. Multivariate analysis showed that clinical remission [5.77 (2.03-16.39), $p=0.001$] was a predictor of good quality of care.

Conclusions : In this large IBD trial bureau, inflammatory bowel disease patients were very satisfied with the quality of care. Domains for quality improvement, such as attention to the impact of IBD on family and work, were identified. (*Acta gastroenterol. belg.*, 2020, 83, 25-31).

Key words : Inflammatory bowel disease, quality of care, patient satisfaction, trial center.

Introduction

Inflammatory bowel diseases (IBD) are chronic gastrointestinal conditions characterized by an unpredictable course with alternating periods of relapse and remission often requiring therapy. Current medical and surgical treatment has greatly improved quality of life of these patients. However, the chronic character of the disease requires close follow-up by specialized IBD providers and concomitant outpatient visits.

Given this frequent, ongoing relationship between IBD patients and their health care providers it is evident that a high quality of care (QoC) in IBD may result in optimising patient outcomes and improving quality of life (QoL) (1,2). When evaluating medical care, there are often discrepancies between the healthcare providers and patients' opinion about the QoC provided and their perception of what is important in care delivery (3,4). Nowadays, healthcare providers increasingly use patient feedback via satisfaction questionnaires in order to evaluate and improve quality performance (5). Indeed, the delivered quality of care may have a large impact

on the health condition of patients. If patients are more satisfied with the care, they will be more compliant, more positive, more cooperative, and more likely to participate in their treatment procedures (6). As a consequence, we can assume that there will be a decreased risk for relapses and complications and patient outcomes will improve.

However, to achieve this, only a limited number of disease-specific patient satisfaction questionnaires is available (7-9). Furthermore, there are several studies that investigated the QoC in general and in IBD (9-11). But so far, little is known about delivered QoC in clinical trials.

Therefore, we developed a questionnaire to evaluate quality of delivered care in patients included in a randomized clinical trial in the tertiary IBD referral center at University Hospitals of Leuven. This survey was used to examine both expectations and experiences of patients about the delivered care, to detect quality improvement areas and design an action plan, to improve care where needed.

Methods

The IBD unit at the University Hospitals of Leuven functions as a referral center for patients suffering from Crohn's disease or ulcerative colitis. Within the IBD unit, the clinical trial bureau manages on average 100-130 IBD patients in early (1b/2) to late (3 and 4) phase clinical trials. Outpatient trial visits are performed daily during working hours by 2 study physicians and 7 study coordinators under the supervision of 3 full-time IBD staff members.

Development of questionnaire

A patient satisfaction questionnaire was developed based on 9 validated surveys and evaluation methods online available. Both IBD-specific and general satisfaction questionnaires were used (7-9,12-17). Each question-

Correspondence to : Sofie Coenen, University Hospitals Leuven, Department of Gastroenterology and Hepatology, Herestraat 49, 3000 Leuven, Belgium. Sofie.coenen@uzleuven.be

Submission date : 28/02/2019

Acceptance date : 02/07/2019

Acta Gastro-Enterologica Belgica, Vol. LXXXIII, January-March 2020

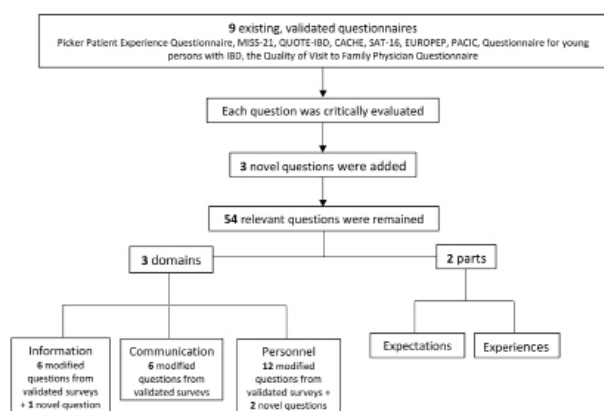


Figure 1. — Development of questionnaire.

naire was critically evaluated by the second author and adjudicated by all co-authors to maintain only relevant questions. These questions were complemented with 3 novel questions, “Do you get a quick referral to another specialist, if necessary?”, “Are prescriptions and certificates easily available?” and “Do you get a reliable judgment about your health state at each visit?”. On the other hand, less relevant questions like “The liquid laxative for colonoscopies should be tolerable”, “The nurses in the IBD center should have specific expertise in IBD”, and “I feel calm after the consultation” were removed. The final questionnaire contained 54 questions translated to Dutch and arranged in one of the following domains : information, communication and staff (Figure 1).

The questions were subdivided into two parts : one part explored what patients considered important and the other part examined how patients experienced the care at the IBD clinical trial center. All questions had to be judged on a 6 scale Likert score ranging from zero (completely disagree) to five (completely agree).

Finally, patients were asked to give a general satisfaction score about the IBD care. This score was assessed on a visual analogue scale (VAS) from zero (terrible) to ten (excellent). Additionally, patients could write down remarks and/or suggestions about the care, the personnel and the provided services (See supplemental table 1).

Study design

Between October 2016 and January 2017, the questionnaire was given to all patients visiting the IBD clinical trial center. Both Crohn’s disease (CD) and ulcerative colitis (UC) patients were included. Processing and statistical analysis of the questionnaire were done anonymously. One team member (MH) received the questionnaires and was aware of which patients completed the questionnaire in order to add some disease specific characteristics (obtained from the electronic medical record) to the collected data.

Statements with the lowest and highest average score were identified in order to define areas of quality improvement. The individual scores per question were

analyzed to determine outliers (patients giving a very low score for most of the questions defined as 0 and 1 on the Likert score and 0-2 on the VAS).

We opted to give the questionnaire a second time after 6 months to patients who had been recently included in a study (< 6 weeks), in order to check the evolution and evaluate the responsiveness of the questionnaire.

The study was submitted and approved by the Ethical Committee of the University Hospitals of Leuven.

Patient characteristics

Socio-demographic characteristics recorded were sex, age, IBD diagnosis (based on radiological, endoscopic and histological findings), disease duration, level of education, marital status, smoking behavior and employment status. Study-specific characteristics recorded were disease activity, type of study, study phase, time since enrollment, time since visiting IBD center and participation in previous clinical trials. To facilitate further processing of these data, each category was recoded in a binary manner. The category ‘employment status’ was divided into two variables : unemployed (including retired, invalid, unemployed and students) and employed (including full time and part time work). For the variable ‘study phase’, we made a distinction between patients in early (1b/2) to late (3 and 4) phase clinical trials. Patients in a phase 3 and a phase 4 trial were taken together, because there were only 3 patients in a phase 4 trial. The disease activity of our CD patients was measured based on Crohn’s Disease Activity Index (CDAI) and Harvey-Bradshaw Index (HBI). For UC patients, the partial Mayo Score/Disease Activity Index and the Simple Clinical Colitis Activity Index (SCCAI) were used to evaluate the disease state.

Statistical analysis

All statistical analyses were performed using the IBM SPSS 24.0 software packages (SPSS Inc., Chicago, IL, USA). Descriptive statistics (median with interquartile range (IQR) or percentage) were used to summarize the distributions of the characteristics in our patients. To identify predictors of lower satisfaction of quality of

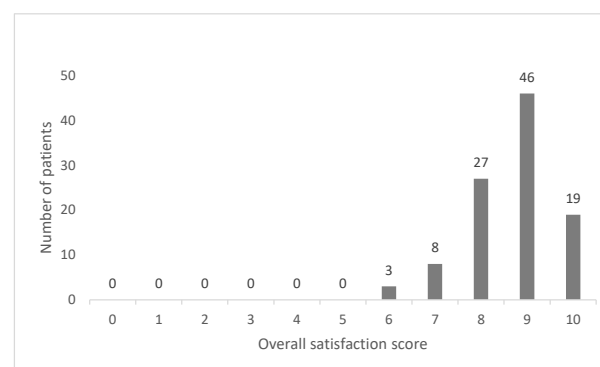


Figure 2. — Patient satisfaction

care uni- and multivariate logistic regression analyses were conducted to evaluate the odds ratios (OR) of variables associated with good satisfaction to quality of care in IBD clinical trial patients (represented as OR with 95% confidence interval (CI)). Therefore, general satisfaction was recorded in a binary manner (with a general satisfaction of 9 or 10 defined as good). Univariate analyses included Chi-Square and Mann-Whitney U statistics. Variables with a p-value <0.20 were included in multivariate analysis. Multivariate analyses were performed using binary logistic regression to define independent predictors of good satisfaction. A p-value <0.050 was considered significant.

Results

Patient characteristics

Between October 2016 and January 2017, the questionnaire was completed by all 107 IBD patients included in one of the ongoing IBD clinical trials, giving a response rate of 100%. Table 1 represents the socio-demographic patient characteristics.

Study-specific characteristics are represented in Table 2. Sixty-seven percent of the included patients were in clinical remission. Half of the patients were visiting the IBD clinical trial unit for 7 years or more but 11% of the patients were relatively new and only known by the team for <2 years. Twenty patients (19%) were included in phase 2 trials, 84 patients (79%) in phase 3 and 3 patients (3%) in phase 4 studies. No patients were included in a phase 1b clinical trial during the study period.

Patient satisfaction

The median (IQR) overall satisfaction score was 9 (8-9) out of 10. A score of 8 was given by 27 patients (25%), 43% of the interviewed patients gave a score of 9 and 19 patients (18%) were very satisfied and assessed their satisfaction with an excellent score of 10 (Figure 2).

a) Individual questions

Three questions had an average score of 5 'completely agree'. One belonged to the first part of the questionnaire, the expectations of the patient. The other best rated questions, receiving an average score of 5, evaluated patients' experiences with communication and study staff (Table 3). Communication of the IBD team was experienced as familiar and the staff was evaluated as friendly and polite.

In contrast, there were 9 questions with an average score of 3 'rather agree'. Four of them were part of the expectation part of the questionnaire, five questions of the experience part. These questions concerned were related to the impact of IBD on quality of life, mental health, family and work. The received information about diet, exercise and daily activities, the improvement of the

Table 1. — Socio-demographic patient characteristics

Number of patients	107
CD	26 (24%)
UC	81 (76%)
Sex	
male	67 (63%)
female	40 (37%)
Median (IQR) age (years)	47 (35-58)
Higher educational level	
primary school	8 (8%)
secondary school	45 (42%)
bachelor degree	39 (36%)
master degree	15 (14%)
Employment status	
employed	65 (61%)
unemployed	42 (39%)
Smoking status	
never	64 (60%)
ex-smoker	33 (31%)
current	10 (9%)
Marital status	
cohabiting	73 (68%)
single	34 (32%)

Table 2. — Study-specific patient characteristics

Number of patients	107
Disease activity at moment of questionnaire completion?	
active*	35 (33%)
remission	72 (67%)
Median (IQR) time of diagnosis (years)	14 (8-21)
Study visit	
0-6 weeks after screening	19 (18%)
≥7 weeks after screening	88 (82%)
Study phase	
phase 2	20 (19%)
phase 3	84 (79%)
phase 4	3 (3%)
Type of trial	
double blind	23 (22%)
open label	84 (79%)
Participation in previous trial	
No	23 (22%)
Yes	84 (79%)
Median (IQR) time visiting IBD clinical trial unit (years)	7 (3-13)

* active disease defined as a CDAI > 150 or HBI > 4 for CD and partial Mayo score ≥ 2 or SCCAI ≥ 3.

mental health status and the attention paid to the impact of the disease on family life and work, were rated as 3 out of 5. Furthermore, the time in waiting room and being treated by the same physician were rated as 'rather agree' (Table 3). No questions were identified with an average score of 0, 1 or 2.

b) Responsiveness of the score

Between October 2016 and January 2017, 17 patients were recently (<6 weeks) enrolled in a randomized controlled trial (RCT) and completed the questionnaire again after 11 weeks. At baseline, the satisfaction score was assessed as almost excellent, with a median (IQR) score of 9 (8-9). The overall satisfaction score was again assessed as almost excellent after 11 weeks, with a median (IQR) score of 8 (8-9).

Table 3. — Best and worst rated questions

	Questions rated as 'totally agree' (score = 5)	Questions rated as 'rather agree' (score = 3)
PART 1: Explored what patients consider important.	I think it's important to get a clear explanation about IBD, the therapeutic strategies and the adverse events of the medication. (INFORMATION/GENERAL)	I think it's important to wait no longer than 15 min. in the waiting room. (INFORMATION/GENERAL)
		I want to choose the date and time of the following visit on my own. (COMMUNICATION)
		I want to be treated by the same doctor. (PERSONNEL)
		The IBD team must pay attention to the impact of my disease on my family life and work. (PERSONNEL)
PART 2: Examined how patients experienced the care at the IBD clinical trial center.	The IBD team communicates with me in a familiar language. (COMMUNICATION)	I receive information about dietary, exercise, daily activities, etc. in the context of IBD. (INFORMATION/GENERAL)
	The IBD team is friendly and polite. (PERSONNEL)	I don't have to wait more than 15 min. in the waiting room. (INFORMATION/GENERAL)
		I'm always treated by the same doctor. (PERSONNEL)
		The IBD team tries to improve my mental health status. (PERSONNEL)
		The IBD team pays attention to the impact of my disease on my family life and work. (PERSONNEL)

Table 4. — Uni- and multivariate analysis

Variable	Univariate analysis		Multivariate analysis	
	Odds ratio [95% CI]	p-value	Odds ratio [95% CI]	p-value
Female	0.758 [0.337 - 1.701]	p=0.501		
Cohabiting	1.600 [0.696 - 3.677]	p=0.267		
> 30 years	1.939 [0.644 - 5.837]	p=0.233		
Higher educational level	0.559 [0.250 - 1.250]	p=0.155	0.553 [0.233 - 1.316]	p=0.181
Active smoking	0.488 [0.123 - 1.938]	p=0.312		
Employed	0.788 [0.347 - 1.788]	p=0.569		
Ulcerative colitis	1.592 [0.642 - 3.947]	p=0.314		
Remission	3.048 [1.311 - 7.083]	p=0.008	5.770 [2.031 - 16.392]	p=0.001
> 6 weeks inclusion	1.146 [0.417 - 3.146]	p=0.791		
Phase 3/4	0.444 [0.148 - 1.336]	p=0.142	0.172 [0.045 - 0.652]	p=0.010
Open label	0.984 [0.382-2.542]	p=0.974		
Previous studies	0.776 [0.295 - 2.038]	p=0.606		

The average score of each question showed very little change compared to the first survey completion. The highest and lowest scoring questions were similar to those listed in Table 3.

Open feedback

Feedback was provided by 21 patients, corresponding to the areas of quality improvement. Patients noted that they wanted more nutritional advice, that the psycho-emotional support could be better and that the relationship between disease and work should be discussed on a more regular base. Besides, the comment was made that they always wanted to be examined by the same physician and that they often had to wait more than 15 minutes before the medication could be administered.

Uni- and multivariate analysis

a) Univariate analysis

Being in remission was the only variable associated with good satisfaction to the provided quality of care in univariate analysis [3.048 (1.311-7.083), p=0.008] (Table 4).

b) Multivariate analysis

In multivariate analysis, 2 variables were significantly associated with satisfaction to the provided QoC. Being in remission was associated with improved satisfaction to quality of care [5.77 (2.03-16.39), p=0.001]. Being included in a phase 3/4 study was identified as a risk

factor for less satisfaction with quality of care [0.17 (0.045-0.652), $p=0.010$] (Table 4).

Discussion

Quality of care is a timely issue in today's clinical practice, especially in chronic diseases such as IBD (18-21). We developed a 54-item questionnaire to evaluate patients' expectations and experiences in an IBD clinical trial center. In this way, we assessed the delivered quality of care and identified areas of improvement.

Our results demonstrate that overall quality of care was reported to be excellent. This is consistent with previous literature describing similar results in patients with IBD. In 2014 *Bortoli et al* published satisfactory ratings of the quality of care in IBD (22). Furthermore, *Jelsness-Jørgensen et al* demonstrated in 2016 an overall good patient satisfaction to the QoC in IBD patients (23). Our data confirmed these findings now also in a setting of randomized clinical trials and identified comparable areas of quality improvement.

A lot of initiatives have been implemented in our IBD trial center to optimize QoC. First of all, the IBD team is a very stable team where most members have >5 years experience in the same team. This certainly enhances collaboration and smooth communication between team members. Towards patients, this creates a factor of stability as patients always see the same faces, allowing them to build a strong relationship. This good relationship between patient and treating physician could also have contributed to the 100% response rate. Secondly, we implemented monthly team meetings since several years to discuss ongoing trials, recruitment and randomization issues and potential concerns. Recently, *Ferman et al* demonstrated that IBD multidisciplinary team meetings appear likely to be effective in assisting complex decision-making in IBD with a positive effect on outcomes (24). Finally, our hospital also obtained JCI accreditation for the third time in 2016, which reflects the strong focus of the hospital on high quality and continuous improvement of patient safety.

The most important area of possible improvement identified in this study, was that more attention should be paid to the impact of IBD on family, work and quality of life. Previous studies demonstrated that physician-patient interactions need to be improved and that the delivered care should be more patient-centered. Physicians are still too focused on curing the disease, less attention is paid to patients' emotions (25,26). Studies revealed that physicians need to integrate work participation more into the patient's disease management plan (27-31). Furthermore, the values, preferences and emotions of the patient's family need to be taken into account as well. *Meenan et al* and *Golics et al* have already demonstrated the importance of involving family members in patient's care, because chronic diseases can be physically and emotionally stressful for the family as well (31,32).

The areas of improvement identified in this prospective study, will be part of the action plan that will be established and implemented in the IBD clinical trial center. Physicians as well as study coordinators will have shared responsibility to improve these action points. Both will have a role in reducing waiting time, although for many RCTs, where experimental drugs need preparation time, this will never be possible. Furthermore, they will make sure that patients are mostly treated by the same physician, and will pay more attention to the impact of IBD on the patient's dietary and exercise pattern, daily activities, work, emotions and QoL.

Being in remission was identified as a strong predictor of good quality of care. Previous studies already demonstrated that patients experiencing less pain or symptoms show higher satisfaction rates (33-35). Our study confirmed these findings. Additionally, multivariate analysis showed that being included in a phase 2 trial was also a predictor of good satisfaction to QoC in contrast to a phase 3 or 4 study. The reason why patients in a phase 3/4 trial are less satisfied than patients in a phase 2 trial is still unknown. Maybe patients who consent to take part in a phase 2 study are more refractory patients with less treatment options left, who therefore are more hopeful and grateful for the time, attention given to them.

One of the strengths of this project was the very high participation rate. All patients visiting the clinical trial center completed the questionnaire. Furthermore, the instrument was easily accessible for each patient and feedback and suggestions could be written down to improve quality of care in the future. Another strength was the difference in disease duration and the period of visiting the IBD trial center for all patients, representing a varied patient population.

Our study also has some limitations. First of all, there were limitations to the anonymous nature of the questionnaire because some additional disease specific characteristics were added to the collected data by one team member (MH). This could have caused a false increase in satisfaction rating. Although patients were informed that their feedback and scores were further analyzed anonymously, this could still have caused a bias. The use of a mailbox, would be an appropriate solution in similar, future projects. Secondly, no control group was added in this project. We could have compared with IBD patients not enrolled in a clinical trial, but these patients are seen in a totally different setting than clinical trial patients. In the future our questionnaire could be tested in another IBD clinical trial center or in clinical trial patients suffering from another chronic disease to test for consistency. Another control group may have been patients who had to stop a clinical trial.

We conclude that IBD clinical trial patients are very satisfied with the delivered quality of care. However, domains that can be subjected to quality improvement, were identified. In the near future, an action plan will be created to deal with these improvement areas and to optimize the quality of delivered care. Furthermore, the

questionnaire must be completely anonymized, to get fair and reliable results. In this way, we will be able to validate this satisfaction questionnaire.

Conflicts of interest

Sofie Coenen, Margo Haeck, and Maja Noman have no conflicts of interest.

Marc Ferrante reports research grant : Janssen, Takeda ; Consultancy : Abbvie, Boehringer-Ingelheim, Janssen, Mitsubishi Tanabe, MSD, Pfizer; Speakers fee : Abbvie, Boehringer-Ingelheim, Falk, Janssen, Lamepro, Mitsubishi Tanabe, MSD, Pfizer, Tramedico.

Gert Van Assche reports financial support for research from Abbott and Ferring Pharmaceuticals ; lecture fees from Janssen, MSD and Abbott; consultancy fees from PDL BioPharma, UCB Pharma, Sanofi-Aventis, Abbott, Abbvie, Ferring, Novartis, Biogen Idec, Janssen Biologics, NovoNordisk, Zealand Pharma A/S, Millenium/Takeda, Shire, Novartis and Bristol Mayer Squibb.

Séverine Vermeire reports financial support for research : MSD, AbbVie, Takeda, Pfizer, J&J ; Lecture fee(s) : MSD, AbbVie, Takeda, Ferring, Centocor, Hospira, Pfizer, J&J, Genentech/Roche ; Consultancy : MSD, AbbVie, Takeda, Ferring, Centocor, Hospira, Pfizer, J&J, Genentech/Roche, Celgene, Mundipharma, Celltrion, SecondGenome, Prometheus, Shire, Prodigest, Gilead, Galapagos.

Acknowledgements

Séverine Vermeire, Gert Van Assche and Marc Ferrante are Senior Clinical Investigators of the Research Foundation - Flanders (FWO), Belgium.

References

- ELKJAER M, MOSER G, REINISCH W, DUROVICOVA D, LUKAS M, VUCELIC B, *et al.* IBD patients need in health quality of care ECCO consensus. *J Crohn's Colitis*. 2008 Jun, **2**(2) : 181-8.
- VAN DER E, VLACHONIKOLIS IG, MUNKHOLM P, NIJMAN J, BERNKLEV T, POLITI P, *et al.* The role of quality of care in health-related quality of life in patients with IBD. *Inflamm Bowel Dis*. 2004, **10** : 392-8.
- LEBOW JL. Consumer assessments of the quality of medical care. *Med Care*. 1974, **12**(4) : 328-37.
- VAN DER EIJK I, VERHEGGEN FW, RUSSEL MG, BUCKLEY M, KATSANOS K, MUNKHOLM P, *et al.* ?Best practice? in inflammatory bowel disease : an international survey and audit. *Eur J Intern Med*. 2004 Apr, **15**(2) : 113-20.
- DONABEDIAN A. The quality of care. How can it be assessed? *JAMA J Am Med Assoc*. 1988, **260**(12) : 1743-8.
- FROJD C, SWENNE CL, RUBERTSSON C, GUNNINGBERG L, WADENSTEN B. Patient information and participation still in need of improvement : evaluation of patients' perceptions of quality of care. *J Nurs Manag*. 2011, **19**(2) : 226-36.
- CASELLAS F, GINARD D, VERA I, TORREJÓN A. Development and testing of a new instrument to measure patient satisfaction with health care in inflammatory bowel disease : the CACHE questionnaire. *Inflamm Bowel Dis*. 2013, **19**(3) : 559-68.
- SADLO A, ALTEVERS J, PEPLIES J, KALTZ B, CLAÄYEN M, BAUER A, *et al.* Measuring satisfaction with health care in young persons with inflammatory bowel disease -an instrument development and validation study. *BMC Health Serv Res*. 2014, **14**.
- VAN DER EIJK I, SIXMA H, SMEETS T, TAVARELA VELOSO F, ODES S, MONTAGUE S, *et al.* Quality of health care in inflammatory bowel disease : Development of a reliable questionnaire (QUOTE-IBD) and first results. *Am J Gastroenterol*. 2001, **96**(12) : 3329-36.
- ALAZRI MH, NEAL RD. The association between satisfaction with services provided in primary care and outcomes in Type 2 diabetes mellitus. *Diabet Med*. 2003, **20** : 486-90.
- HIRSHAT, ATCHISON JW, BERGER JJ, WAXENBERG LB, LAFAYETTE-LUCEY A, BULCOURF BB, *et al.* Patient satisfaction with treatment for chronic pain : predictors and relationship to compliance. *Clin J Pain*. 2005, **21**(4) : 302-10.
- MARCINOWICZ L, RYBACZUK M, GREBOWSKI R, CHLABICZ S. A short questionnaire for measuring the quality of patient visits to family practices. *Int J Qual Heal Care*. 2010, **22**(4) : 294-301.
- MEAKIN R, WEINMAN J. The "Medical Interview Satisfaction Scale" (MISS-21) adapted for British general practice. *Fam Pract*. 2002, **19**(3) : 257-63.
- WENSING M, VAN LIESHOUT J, JUNG HP, HERMSEN J, ROSEMAN T. The Patients Assessment Chronic Illness Care (PACIC) questionnaire in The Netherlands : a validation study in rural general practice. *BMC Health Serv Res*. 2008, **8**(1) : 182.
- OTTONELLO M, FRANCHIGNONI F, GIORDANO A, BENEVOLO E. Patient satisfaction with hospital rehabilitation : Validation of the SAT-16 questionnaire through Rasch analysis. *Minerva Med*. 2012, **103**(1) : 1-11.
- JENKINSON C, COULTER A, REEVES R, BRUSTER S, RICHARDS N. Properties of the Picker Patient Experience questionnaire in a randomized controlled trial of long versus short form survey instruments. Vol. 25, *Journal of Public Health Medicine*. 2003. p. 197-201.
- BJERTNAES OA, LYGSTAD I, MALTERUD K, GARRATT A. The Norwegian EUROPEP questionnaire for patient evaluation of general practice : Data quality, reliability and construct validity. *Fam Pract*. 2011, **28**(3) : 342-9.
- KAPPELMAN MD, PALMER L, BOYLE BM, RUBIN DT. Quality of care in inflammatory bowel disease : A review and discussion. Vol. 16, *Inflammatory Bowel Diseases*. 2010. p. 125-33.
- MELMED GY, SIEGEL C A. Quality improvement in inflammatory bowel disease. *Gastroenterol Hepatol (N Y)*. 2013, **9**(5) : 286-92.
- MOREELS TG, LANTHIER N. The quest for quality. *Acta Gastroenterol Belg.*, 2018, **81**(1) : 3-4.
- PANÉS J, O'CONNOR M, PEYRIN-BIROULET L, IRVING P, PETERSSON J, COLOMBEL J-F. Improving quality of care in inflammatory bowel disease : what changes can be made today? *J Crohns Colitis*. 2014, **8**(9) : 919-26.
- BORTOLI A, DAPERNO M, KOHN A, POLITI P, MARCONI S, MONTERUBBIANESI R, *et al.* Patient and physician views on the quality of care in inflammatory bowel disease : Results from SOLUTION-1, a prospective IG-IBD study. *J Crohn's Colitis*. 2014, **8**(12) : 1642-52.
- JELSNES-JØRGENSEN L-P, BERNKLEV T, HOVDE Ø, PRYTZ BERSET I, HUPPERTZ-HAUSS G, MOUM B, *et al.* Patients' perceptions of quality of care and follow-up in inflammatory bowel disease. *Scand J Gastroenterol*. 2016, **51**(4) : 434-41.
- FERMAN M, LIM AH, HOSSAIN M, SLOW GW, ANDREWS JM. Multidisciplinary team meetings appear to be effective in inflammatory bowel disease management : an audit of process and outcomes. *Intern Med J*. 2018.
- BECK RS, DAUGHTRIDGE R, SLOANE PD. Physician-patient communication in the primary care office : a systematic review. *J Am Board Fam Pract*. 2002, **15**(1) : 25-38.
- RUIZ-MORAL R, PÉREZ RODRÍGUEZ E, PÉRULA DE TORRES LÁ, DE LA TORRE J. Physician-patient communication : A study on the observed behaviours of specialty physicians and the ways their patients perceive them. *Patient Educ Couns*. 2006 Dec, **64**(1-3) : 242-8.
- RESTALL GJ, SIMMS AM, WALKER JR, GRAFF LA, SEXTON KA, ROGALA L, *et al.* Understanding work experiences of people with inflammatory bowel disease. *Inflamm Bowel Dis*. 2016, **22**(7) : 1688-1697.
- BOONEN A, CHORUS A, MIEDEMA H, VAN DER HEIJDE D, VAN DER TEMPEL H, VAN DER LINDEN S. Employment, work disability, and work days lost in patients with ankylosing spondylitis : a cross sectional study of Dutch patients. *Ann Rheum Dis*. 2001, **60** : 353-8.
- YELIN E, MEENAN R, NEVITT M, EPSTEIN W. Work disability in rheumatoid arthritis : Effects of disease, social, and work factors. *Ann Intern Med*. 1980, **93**(4) : 551-6.
- VAREKAMP I, VAN DIJK FJH. Workplace problems and solutions for employees with chronic diseases. *Occup Med (Chic Ill)*. 2010, **60**(4) : 287-93.
- MEENAN RF, YELIN EH, NEVITT M, EPSTEIN W V. The impact of Chronic disease. A Sociomedical Profile of Rheumatoid Arthritis. *Arthritis Rheum*. 1981, **24**(3) : 544-9.
- GOLICS CJ, BASRA MKA, SALEK MS, FINLAY AY. The impact of patients' chronic disease on family quality of life : an experience from 26 specialties. *Int J Gen Med*. 2013, **6** : 787-98.
- JACKSON JL, CHAMBERLIN J, KROENKE K. Predictors of patient satisfaction 1. *Soc Sci Med*. 2001, **52** : 609-620.



34. SHIRLEY ED, SANDERS JO. Patient Satisfaction : Implications and Predictors of Success. *J Bone Jt Surgery-American*, 2013, **95**(10) : e69-1-4.

35. SERBER ER, CRONAN T A., WALEN HR. Predictors of patient satisfaction and health care costs for patients with fibromyalgia. *Psychol Health*. 2003, **18**(6) : 771-87.

