ORIGINAL PAPERS

Development of quality standards in inflammatory bowel disease management and design of an evaluation tool of nursing care

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ABSTRACT

Background and aims: nursing management of inflammatory bowel disease (IBD) is highly relevant for patient care and outcomes. However, there is evidence of substantial variability in clinical practices. The objectives of this study were to develop standards of healthcare quality for nursing management of IBD and elaborate the evaluation tool "Nursing Care Quality in IBD Assessment" (NCQ-IBD) based on these standards.

Methods: a 178-item healthcare quality questionnaire was developed based on a systematic review of IBD nursing management literature. The questionnaire was used to perform two 2-round Delphi studies: Delphi A included 27 IBD healthcare professionals and Delphi B involved 12 patients. The NCQ-IBD was developed from the list of items resulting from both Delphi studies combined with the Scientific Committee's expert opinion.

Results: the final NCQ-IBD consists of 90 items, organized in 13 sections measuring the following aspects of nursing management of IBD: infrastructure, services, human resources, type of organization, nursing responsibilities, nurse-provided information to the patient, nurses training, annual audits of nursing activities, and nursing research in IBD. Using the NCQ-IBD to evaluate these components allows the rating of healthcare quality for nursing management of IBD into 4 categories: A (highest quality) through D (lowest quality).

Conclusion: the use of the NCQ-IBD tool to evaluate nursing management quality of IBD identifies areas in need of improvement and thus contribute to an enhancement of care quality and reduction in clinical practice variations.

Key words: Delphi technique. Inflammatory bowel disease. Nursing care. Standard of care. Total quality management.

INTRODUCTION

Inflammatory Bowel Disease (IBD) is progressively becoming more prominent across industrialized nations' healthcare systems. For instance, Crohn's disease incidence reports in Europe fall between 2.5 and 7.5 cases per 100,000 population per year (1,2). Based on recent years' increase in reported cases, current incidence rates are estimated at about 9 cases per 100,000 population per year (3-6).

Most cases of IBD –which include Crohn's disease and ulcerative colitis– present in young individuals during their formative or working-age years. This timing contributes significantly to IBD's major negative impact, both in the clinical sense and also in terms of the individual's quality of life (7). The extent of personal and socioeconomic consequences is reflected in the increasing consumption of healthcare resources, economic costs, and impact on work productivity (8). IBD treatment goals include: achieve remission and maximize length of remission, minimize medication side-effects, reduce symptoms, resolve any complications that may arise, and improve patients' quality of life. IBD management requires a multidisciplinary approach with interaction among doctors, nurses, surgeons, dieticians, and social workers, among others (1,2).

Growing awareness of the key role of such multidisciplinary approach to IBD management has materialized in specific initiatives from some hospitals. Such initiatives have created general outpatient offices for nurse consultation and some have even developed Comprehensive Care Units for IBD (9-12). A previous study, specifically designed for Gastroenterology clinical centers, investigated different organizational models of nursing management of IBD in Spain, including responsibilities and resources available to IBD-specialized nursing. The findings of this 2009 survey showed significant heterogeneity regarding health care organizational nursing models for IBD and the impact on patients (13). Based on these findings, the research project described here was designed with two main objectives: First, to devel-

op standards of quality to homogenize IBD nursing care; and second, based on said standards, to design a tool to evaluate the nursing care quality in IBD (NCQ-IBD).

METHODS

Overall design

Two Delphi studies were performed, one intended for healthcare professionals (Delphi A) and a second one aimed at patients (Delphi B)

Phase I – Delphi A (healthcare professionals)

The Delphi method is a consensus technique, consisting of a series (two or more) of consultations (rounds) by post or email to an expert panel, using questionnaires with questions that respondents answer by the first time (first round), without hints about what may respond the rest of the panel members. In a second round, there is a feedback in which each panelist is informed about the results of the previous round, and asked to respond again, in order to improve the degree of consensus among experts. This method ensures the anonymity for each respondent.

Our 2-round Delphi study for professionals took place between March and June of 2010 involving 27 experts from 9 of the 17 Autonomous Communities (regions) in Spain. Twelve experts were gastroenterologists, 12 nurses, and 3 surgeons (14). The questionnaire's 178 items stemmed from a systematic literature review on the effectiveness of the different existing organizational models of nursing management of IBD (15). One of the most relevant documents was the 2009 IBD standards Group document (16). The items selection was performed by the members of the project scientific committee (SC) formed by 3 gastroenterologists and 5 nurses.

The Delphi questionnaires included two kinds of items. The first type were statements reflecting recommendations (e.g., "Patient must receive a direct line telephone number") with possible answers on a scale of 9 points, where "1" stood for "not important at all" and "9" stood for "very important". The second type items were statements soliciting answers on a continuous scale (e.g., "Minimum amount of days per week that the IBD nursing unit should see patients"). The final questionnaire items were organized under 6 sections related to the IBD nursing care: Infrastructure (44 items); process (65 items); management and patient follow-up (38 items); specialized nurse training (23 items); nursing research (8 items); and suggestions section, where panel members were encouraged to make recommendations. Based on suggestions from panel members, the number of items for the second-round questionnaire was increased to 182. In order to facilitate item re-evaluation during this round, the documentation received by each panel member included for each item response the mean, the standard deviation, and the panel member's own response to the item during the first round.

Phase II – Delphi B (IBD patients)

The patients' Delphi study was done between July and October 2010. The first-round questionnaires were sent to each member of the SC. This person, then, selected potential study participants randomly from all the patients based on the order at which they arrived to the nurse consultation office. The study participant inclusion criteria were: IBD patients 18 years of age or older, secondary school completed, at least five years since IBD diagnosis, and reporting at least two visits to the nursing care service in the previous year. Finally, 12 patients from six hospitals of five regions in Spain were selected as panel members. Second-round questionnaires were sent directly to each patient by electronic mail.

The SC designed the patients' questionnaire based on the healthcare professionals' questionnaire reducing the number of items, according to the ability of patients to respond, to 123. The items were organized in four sections: Infrastructure (35 items); process (60 items); management and patient follow-up (22 items); and specialized nurse training (6 items).

Phase III – Selection of standard of quality items

Once data from professionals and patients Delphi studies were analyzed, all quality of care standard items were combined into a single list resulting in 193 items. This standards-of-quality item list became the working document used by the SC to rate each item into one of three categories: high, medium, or low importance for measuring the quality of care. The first step in the classification process was to rate items based on the scores assigned by panel members while weighing the relative importance of health professionals' contributions *vs.* patients' contributions. Before the rating and weighing process started, however, all 193 items were organized into 16 sections to group items by response scale (1-9 scale *vs.* continuous) as well as by topic (infrastructure, process, etc.).

– *Categories: Cut-off points.* In a first meeting, the SC established classification criteria to use as reference points in the rating of the standards of quality in order to facilitate scoring each of the 16 sections. The SC agreed on 3 cut-off points for each of the items on scales from 1 to 9 for assigning the importance for measuring the quality of care: high, medium, or low importance. Items scored the highest by panel members were considered highly important, fundamental or basic, whereas the ones receiving the lowest scores were labeled as low important for quality aspects. The items ranked below "low importance" were eliminated in the NCQ-IBD. For continuous scale items two complementary percentiles (i.e., both percentiles must add up to 1) were used to define three quality categories for each item: Excellent, medium, and basic. For instance, for item 11 "Available on-demand nursing

appointments for IBD days per week" the 0.16 and 0.84 percentiles were used resulting in "Excellent" above 4.4, "Basic" below 2.5, and "Medium" between 2.5 and 4.4 days per week.

– *Data weighting.* The SC used weights to assign more or less relevance to the answers from each panel (professionals or patients) according to the item's topic. SC experts assigned weights between 0 and 1 to healthcare professionals' scores (healthcare professional weight), and a complementary weight (1-healthcare professionals weight) to patients' score. Thus, for instance, a weight of 1 meant that only healthcare professionals' opinions were deemed relevant, a weight of 0 meant that only patients' opinions were deemed relevant, and a weight of 0.50 for each score meant that both opinions were deemed equally relevant. The sum of the assigned weights to healthcare professionals and to patients had to add up to 1.

In order to avoid SC members' opinions biasing each other's scoring, each member was given a folder with a copy of the questionnaire so that they could score each section privately. Each SC member entered their score in the corresponding boxes. From these values the mean was then calculated and used as reference point for the rating and weighing of the standards of quality.

During a second meeting, items considered dispensable (with a final score below the low importance cut-off point) by SC experts were eliminated to make the instrument more efficient. Items specific to nursing management of IBD were kept, together with the most objective items. Finally, this streamlined version was used to build the NCQ-IBD tool for the evaluation of nursing care quality in IBD.

RESULTS

Finally, 90 items (quality of care standards) were elaborated; table I shows the final cut-off points used for rating the item importance (items on scales from 1 to 9), the item excellence category (continuous scale items), the weighing values, as well as the number of final items for each section. The NCQ-IBD kept 90 of the initial 193 items. The first column displays the heading of the section of the list of items resulting from merging the healthcare professional and patient Delphi questionnaires. The second column shows the corresponding number of items. Items included in the questionnaire after eliminating the dispensable ones are specified in the third column. The three following columns present the SC-assigned cut-off points used for rating the items importance and excellence categories. Weighing values are specified next. Items included in just one of the Delphi questionnaires (answered only by either healthcare professionals or by patients) do not require weighing values. For building the NCQ-IBD tool (Appendix 1), each quality standard was operationalized into a specific, quantifiable question. The final NCQ-IBD tool is comprised of 90 items organized in 13 sections. For prac-

tical use, the NCQ-IBD is supplemented by an instruction manual specifying who must complete the instrument and how to respond to the questions. It also includes a glossary of terms to avoid ambiguity in the interpretation of items.

Once the NCQ-IBD was designed, the SC met to agree upon a rating of nursing healthcare quality in IBD to facilitate the operationalization of the quality standards instrument using the items values for assigning a quality of nursing care level for a specific IBD service. The SC accomplished the task of assigning final ratings to the different models of nursing healthcare based on item grouping. First, the SC defined quality standards at three levels of quality of care. Items on scales from 1 to 9 were assigned one of three labels: Level IS-Basic (high importance), Level IIS-Medium (medium importance), or Level IIIS-Excellent (low importance). Continuous items were assigned similar labels: Level IC-Basic, Level IIC-Medium, or Level IIIC-Excellent (column 3, Appendix 1). This classification reflects the importance the panel members assigned to the 1-9 scale indicators and the minimum criteria assigned to continuous indicators. Out of the 90 items included in the list of care standards were 67 1-9 scale and 23 were continuous. Out of the 67 1-9 scale items panel members ranked 20 as level IS or Basic, 33 as level IIS or Medium, and 14 as level IIIS or Excellent. In regards to the care standard, criteria for level IS-IC represent the very basic, i.e., the minimum level expected for any rating in quality healthcare. Criteria for level IIS-IIC items correspond to medium healthcare quality; and Level IIIS-IIIC items denote excellent quality care.

As it may be that a particular service was well evaluated fulfilling correctly many low relevant items, the SC decided to set items that should necessarily be met for each level of quality care. For this reason, it was considered that the quality level of nursing care in IBD depends on two conditions: a) Meeting specific required items at each of the levels examined (Table II); and b) totaling to a minimum number of items for reaching a determinate quality level (Table III). Accordingly, once the items were classified by levels four categories for "Nursing care quality in IBD" were created labeled A, B, C, and D. Category A corresponds to the highest quality nursing care model and category D corresponds to the lowest quality model. Criteria for each of these four categories are described in table III. Thus, for those cases where either one of the conditions are not met, the quality of nursing care model will be placed in the category according to the highest common rating reached in both set of criteria illustrated in tables II and III.

DISCUSSION

Research describing nursing best practices in IBD is scarce. Thus, this study explores quality standards that allow identify responsibilities that nursing should foster as well as the resources they should have available to potentially improve quality and patients outcomes. As part of this

Table I. Ratings and weights of the different measurement sections to evaluate nursing care quality in IBD

Indicators	# of items by Section (193)	# of final items (90)	Cut-off points used for rating the item importance						Weights	
			Scale 1 to 9 (S)			Continuous (C)				
			III-S	II-S	I-S	I-C	II-C	III-C	Healthcare professionals	Patients
Infrastructure										
Environment of IBD care[1]	3	0	NA			< 0.25	0.25-0.75	> 0.75	NA	
Minimum IBD-related services[1]	4	3	NA			< 0.16	0.16-0.84	> 0.84	0.51	0.49
Space identification and description[2]	14	3	7.00	7.50	8.19	NA			0.49	0.51
Nurse Consultation Office resources[2]	11	6	7.86	8.33	8.71	NA			0.51	0.49
Human resources: Healthcare professionals[1]	8	6	NA			< 0.26	0.26-0.74	> 0.74	Only professionals	
Human resources: patients[2]	8	0	7.50	8.00	8.50	NA			Only patients	
Specialists available for referral[2]	7	4	7.13	7.63	8.19	NA			0.54	0.46
Process										
Nursing staff responsibilities[2]	38	27	7.13	7.69	8.13	NA			0.59	0.41
Organization of IBD management[1]	17	8	NA			< 0.23	0.23-0.77	> 0.77	0.54	0.46
Organization to contact IBD patients[2]	14	4	7.50	8.00	8.50	NA			0.53	0.47
Management and patient follow-up										
IBD management quality indicators[2]	25	6	6.29	7.07	7.93	NA			0.64	0.36
Information to patient provided by nurses[2]	11	6	7.07	7.57	8.07	NA			0.39	0.61
Training										
Training plan[2]	20	10	7.00	7.50	8.00	NA			0.51	0.49
Training time[1]	5	3	NA			< 0.23	0.23-0.77	> 0.77	Only professionals	
Research										
Research responsibility[2]	3	1	7.64	8.04	8.37	NA			Only professionals	
Research performed[1]	5	3	NA			< 0.41	0.41-0.59	> 0.59	Only professionals	

IBD: Inflammatory bowel disease; 1Continuous; 2Measure evaluation scale from 1 to 9 (1 = not important at all, 9 = very important); NA: Not applicable.

investigation, two Delphi studies were carried out targeting both healthcare professionals and patients. Based on the information provided by these studies, a list was compiled which included care standards regarding resources, processes, training and research, among others. The NCQ-IBD was designed from such list of quality standards. This tool allows an assessment rating the quality of care provided by nurses working at IBD services. The NCQ-IBD categorizes nursing quality of care into four categories from A (highest) to D (lowest).

Results of an earlier survey identified both the responsibilities fulfilled by nurses as well as the resources available for the nursing management of IBD in Spain. Among the main findings, significant effects different nursing organizational structures have on IBD patients' outcomes were reported (13). The paucity of similar instruments calls for the development of tools such as the NCQ-IBD to facilitate assessing current nursing management approaches to IBD care. The application of this tool will assist generate strategies for the improvement of IBD management.

These findings as well as the instrument should be assessed within the context of potential limitations not uncommon in Delphi studies and instrument design. For instance, panel members may not fully represent the populations of interest since they were not selected by randomized sampling. They represent a convenience sample, in which some selection bias may have occurred. To maximize representation –within the scope of the study– data from both healthcare professionals and patients across the country and care levels were collected. Since the final panel was composed of 27 healthcare professionals (12 gastroenterologists, 12 nurses, and 3 surgeons) and 12 pa-

Table II. Criteria needed for the rating of nursing care quality in IBD

Nursing care quality standards in inflammatory bowel disease	D	C	B	A
1	Space available for IBD-specific nursing consultation office		X	X	X
4	Database			X	X
6	Computer		X	X	X
11	Available on-demand nursing appointments for IBD (days per week)		< 2	4-2	> 4
14	Minimum full-time equivalent (FTE) of professionals allocated to IBD management specifically: Nurses allocated to nursing consulting office of IBD		> 0 ≤ 0.5	≥ 0.5 ≤ 1	≥ 1
29	Wait time (in working days) for first regular appointment with nursing		> 12	6-12	< 6
31	Direct access telephone helpline for patients			X	X
34	IBD nurses prioritize needs originating from patients calling nursing				X
37	Monitor follow-up and adherence to biologic drug treatments				X
42	Provide health education to IBD patients		X	X	X
47	Offer a patient helpline to disseminate general and specific IBD information			X	X
61	Administer questionnaires, tests, and indices to learn the patients' biopsychosocial characteristics				X
62	Nursing must report resources available for IBD management (e.g., consultation office hours, operation)		X	X	X
68	Nurses apply CPG or protocols			X	X
84	Minimum hours of IBD-specific training for nurses in 2 previous years			20-40	> 40
87	Nursing reviews its activities and outcomes annually			X	X
Mínimum number of specific ítems for each category of healthcare quality		5	13	16

IBD: Inflammatory bowel disease; A: Highest quality nursing care model; D: Worst quality nursing care model (fails to meet minimum requirements for category C).

Table III. Rating of nursing care quality in IBD

	Number of items needed for each level						
	Scale 1 to 9 (S)			Continuous (C)[d]			
HEALTHCARE quality level	Items I-S[a]	Items II-S[b]	Items III-S[c]	Items I-C	Items II-C	Items III-C	Specific required items[e]
A	10	15	7			12	A (16)
B	10	15			12[f]		B (13)
C	10						C (5)
D	Lower than C						D

IBD: Inflammatory bowel disease; A: Highest quality nursing care model; D: Lowest quality nursing care model (fails to meet minimum requirements for category C). [a]20 available items; [b]33 available items; [c]14 available items; [d]23 available items. [e]Rating of nursing care quality must satisfy the specific required item of the corresponding category (see table II). [f]At least 12 items from level II-C and/or III-C must be satisfied.

tients from nine Spanish regions, the risk of a biased expert panel and, thus, skewed scores leading to invalid results, is extremely low.

Additionally, the set of indicators included may not be comprehensive. However, this is highly unlikely since the instrument includes the most relevant items for its intent due to the methods followed: a systematic search for standard indicators in relevant literature; a preliminary compilation of identified standard indicators describing different nursing management models of IBD; and the SC's revision of the list of identified standard indicators. Further, another potential threat to the creation of standard indicators is the influence experts may exert on each other's opinions. In this study this source of bias was eliminated by using the Delphi method. By this method, experts only interact during the second round of the study and responses are kept confidential throughout. The development of similar instruments in previous Delphi studies establishes the validity of this methodology (17-21). Finally, the instrument's main limitation resides in its rating system based on the SC's expert assessment since the rating system is pending of being applied in the real world.

Among the project's strengths is that the best suited methodology for the design of a measure of quality of care such as NCQ-IBD was followed starting with a rigorous systematic review of literature about the effectiveness of the different nursing management models and behaviors in IBD (15). Based on the analysis of this empirical evidence, two separate Delphi questionnaires were designed for both healthcare professionals with extensive IBD experience and patients with at least five years from diagnosis to evaluate standards of structure, process, research and training. Additionally, once validated, the NCQ-IBD will fill in the gap in the literature of validated indicators of IBD care quality uncovered by the systematic review. Motivated by the patent need for measure development in this specialized field, through this study the most relevant standard indicators of quality were selected, operationalized, and combined into a user-friendly instrument that assesses the nursing care quality in IBD.

The standards developed in this study have contributed to the identification of a set of requirements –such as resources, processes, and training and research– needed by nursing to provide satisfactory levels of IBD care. The NCQ-IBD could be an effective tool to evaluate the healthcare provided specifically by nursing. Based on its ratings, minimum acceptable quality standards in healthcare, research, and training can be identified and outlined. Therefore, the NCQ-IBD provides a powerful tool to reduce large amounts of information into useful specific quality standards. These standards can then be applied by healthcare providers, patient associations, and the Healthcare Administration to homogenize IBD management protocols, reduce clinical practice variations, and improve nursing care in IBD. Ultimately, these improvements will result in better outcomes for IBD patients.

ACKNOWLEDGEMENTS

Appendix. Nursing Care Quality in IBD Assessment (NCQ-IBD)

N.° of items		I-S	II-S	III-S	I-C	II-C	III-C
				Item Rating			
90	NURSING CARE QUALITY IN INFLAMMATORY BOWEL DISEASE ASSESSMENT (NCQ-IBD)	I-S	II-S	III-S	I-C	II-C	III-C
	Infrastructure for IBD management (Yes/No)	If yes					
1	Space available for IBD-specific nursing consultation office	I-S					
2	Medical and Nursing consultation offices are clearly identified with door signs	II-S					
3	Area allocated to IBD care is marked in hospital layout plan	III-S					
	Resources available for nursing management of IBD						
4	Database	I-S					
5	Direct access telephone helpline for patients	I-S					
6	Computer	I-S					
7	Electronic mail	II-S					
8	Electronic patient's clinical history	II-S					
9	Patient educational materials	II-S					
	Services allocated to IBD management (circle time range closest to the one in your institution)				Number of days per week		
10	Available on-demand medical appointments for IBD				< 2.5	2.5-4.5	> 4.5
11	Available on-demand nursing appointments for IBD				< 2.5	2.5-4.4	> 4.4
12	Available on-demand nutrition appointments for IBD				< 1	1	> 1
	Human resources allocated to IBD management (circle range closest to the one in your institution)				Number of FTEs		
	Number of FTEs of professionals allocated to IBD management specifically						
13	Gastroenterologists / digestive system specialists				< 1	1-2	> 2
14	Nurses allocated to nursing consulting office of IBD				< 1	1	> 1
15	Ostomy-specialized nursing staff				< 1	1	> 1
	Number of FTEs allocated to IBD management by healthcare professionals shared with other specialties						
16	Dietician				< 0.5	0.5-1	> 1
17	Psychologist				< 0.5	0.5-1	> 1
18	Administrative staff for IBD appointments and database management				< 0.5	0.5-1	> 1

Appendix 1 (Cont.) Nursing Care Quality in IBD Assessment (NCQ-IBD)

N.° of items		Item Rating					
		I-S	II-S	III-S	I-C	II-C	III-C
90	NURSING CARE QUALITY IN INFLAMMATORY BOWEL DISEASE ASSESSMENT (NCQ-IBD)						
	Specialists available for referrals (Yes/No)	If yes					
	Specialists available for referrals with IBD experience such as:						
19	Gastrointestinal surgeon	I-S					
20	Rheumatologist	II-S					
21	Obstetrician/gynecologist	III-S					
22	Dermatologist	III-S					
	Organization in IBD management (circle time range closest to the one in your institution)				Times		
23	Hours per day allocated to outpatient consultation with a nurse in IBD				< 3	3-5	> 5
24	Minutes allocated to first outpatient consultation with a nurse				< 22	22-30	> 30
25	Minutes allocated to following outpatient consultations with a nurse				< 11	11-21	> 21
26	Minutes allocated to first outpatient consultation with a nurse post-ostomy				< 20	20-30	> 30
27	Minutes per day of outpatient consultation with a nurse to attend walk-in patients				< 40	40-60	> 60
28	Minimum number of times per year that nursing staff should assess IBD patients				< 2	2-4	> 4
	Maximum IBD patient waiting time:						
29	Wait time (in working days) for first regular appointment with nursing				> 12	6-12	< 6
30	Wait time (in minutes) in nursing office's waiting room				> 30	15-30	< 15
	Organization to contact IBD patient (Yes/No)	If yes					
	Information given to the patient:						
31	Direct access telephone helpline for patients	I-S					
32	Name of nurse contact	I-S					
33	Patient must be asked for contact telephone number	II-S					
34	IBD nurses prioritize needs originating from patients calling nursing	III-S					
	Nursing responsibilities in IBD management (Yes/No)	If yes					
35	Educate patients in medication self-administration	I-S					
36	Perform regular follow-up of patients according to each type of treatment	I-S					
37	Monitor follow-up and adherence to biologic drug treatments	I-S					
38	Monitor follow-up and adherence to non-biologic drug treatments	II-S					
39	Supervise blood work between visits for those drugs requiring monitoring	II-S					
40	Review medication during consultation: drug information, secondary effects (in short- and long-term)	II-S					
41	Modify treatment protocol per agreement between physician and nursing staff	II-S					
42	Provide health education to IBD patients	I-S					
43	Promote self-care	II-S					
44	Perform health promotion and lifestyle activities	II-S					
45	Provide dietary advice	II-S					
46	Maintain priority appointments	I-S					
47	Offer a patient helpline to disseminate general and specific IBD information	I-S					
48	Refer problems related to the ostomy pouch to a specialist	I-S					
49	Assess patient's nutritional status	II-S					
50	Implement educational activities for professionals related to IBD care	II-S					
51	Manage walk-ins to avoid increasing wait time for patients with an appointment	II-S					
52	Provide support services for patient and family member groups dealing with IBD diagnosis and lifestyle changes	II-S					
53	Be the link among the patient, the multidisciplinary medical team and Primary Care	II-S					
54	IBD nursing staff must visit admitted patients	II-S					
55	Inform the patient upon discharge	II-S					
56	Inform and counsel patient to aid in clinical decisions	II-S					
57	Coordinate different IBD-related resources (dermatology, rheumatology, gynecology, general surgery, ophthalmology, nutrition).	II-S					
58	Offer patient smoking cessation help	III-S					
59	Supervise the observation of diagnostic tests completion	III-S					

(Continuation in next page)

Appendix 1 (Cont.) Nursing Care Quality in IBD Assessment (NCQ-IBD)

N.° of items		Item Rating					
		I-S	II-S	III-S	I-C	II-C	III-C
90	NURSING CARE QUALITY IN INFLAMMATORY BOWEL DISEASE ASSESSMENT (NCQ-IBD)						
60	Take patient clinical history and perform physical exam to assess IBD symptoms	III-S					
61	Administer questionnaires, tests, and indices to learn the patients' biopsychosocial characteristics	III-S					
Information to patient provided by nurses (Yes/No)		If yes					
	Nursing:						
62	Nursing must report resources available for IBD management (e.g., consultation office hours, operation)	I-S					
63	Informs patients about diagnostic tests performed	II-S					
64	Provides verbal plain-language information regarding the disease status, its progress, and physical exams	II-S					
65	Provides written plain-language information regarding the disease status, its progress, and physical exams	II-S					
66	Provides didactic audio or video materials or webpage address covering diagnosis, treatment and self-care information	III-S					
67	Provides contact information for relevant patient groups or associations.	III-S					
Quality indicators in IBD management (Yes/No)		If yes					
68	Nurses apply CPG or protocols	II-S					
	Assess aspects of the patient's biopsychosocial characteristics such as:						
69	Classification of IBD	II-S					
70	IBD activity indices	II-S					
71	Treatment Compliance Tests	II-S					
72	Quality of life Questionnaires	III-S					
73	Depression and anxiety scales	III-S					
IBD training for nurses (Yes/No)		If yes					
74	Training plan in place for IBD-specialized nursing staff	I-S					
	Nursing staff are trained specifically in:						
75	IBD clinical aspects	I-S					
76	Skills in communication, patient support, and stress management	I-S					
77	Ostomy care	I-S					
78	Nutrition and diets	I-S					
	Nursing staff receive training in:						
79	IBD classification	II-S					
80	IBD activity indices	II-S					
81	Treatment compliance tests	II-S					
82	Quality of life questionnaires	III-S					
83	Depression and anxiety scales	III-S					
Time allocated to IBD training (circle time range closest to the one in your institution)					Number of:		
	Hours a nurse has allocated to training in previous two years:						
84	IBD				< 40	40-60	> 60
85	Ostomies				< 20	20-35	> 35
86	Clinical sessions nursing participates in per month				< 1	1-2	> 2
Annual reviews of IBD nursing activity and outcomes (Yes/No)		If yes					
87	Nursing reviews its activities and outcomes annually	II-S					
Nursing research in IBD (Circle range closest to the one in your institution)					Number:		
	In the last 5 years nursing has participated in:						
88	Research projects				< 3	3-5	> 5
89	Conference presentations				< 4	4-5	> 5
90	Journal publications				< 2	2-3	> 3

REFERENCES

1. Shivananda S, Lennard-Jones J, Logan R, Fear N, Price A, Carpenter L, et al. Incidence of inflammatory bowel disease across Europe: is there a difference between north and south? Results of the European Collaborative Study on Inflammatory Bowel Disease (CD-IBD). Gut 1996;39:690-7.

2. Saro Gismera C, Lacort Fernández M, Argüelles Fernández G, Antón Magarzo J, García López R, Navascues CA, et al. Incidencia y prevalencia de la enfermedad inflamatoria intestinal en Gijón, Asturias, España. Gastroenterol Hepatol 2000;23:322-7.

3. Nerich V, Monnet E, Etienne A, Louafi S, Ramée C, Rican S, et al. Geographical variations of inflammatory bowel disease in France: A study based on national health insurance data. Inflamm Bowel Dis 2006;12:218-26.

4. Sinci BM, Vuceli B, Persi M, Brnci N, Erzen DJ, Radakovi B, et al. Incidence of inflammatory bowel disease in Primorsko-goranska County, Croatia, 2000-2004: A prospective population-based study. Scand J Gastroenterol 2006;41:437-44.

5. Vind I, Riis L, Jess T, Knudsen E, Pedersen N, Elkjaer M, et al. Increasing incidences of inflammatory bowel disease and decreasing surgery rates in Copenhagen City and County, 2003-2005: a population-based study from the Danish Crohn colitis database. Am J Gastroenterol 2006;101:1274-82.

6. Saro C, de la Coba C, Lacort M, et al. Changes in Incidence of Inflammatory Bowel Disease during the Last 15 years: A hospitalization al prospective population-based study from Gijón (Spain) (1992-2006). Gut 2007;39(Supl. 1):A129.

7. Casellas F, Arenas JI, Baudet JS, Fábregas S, García N, Gelabert J, et al. Impairment of health-related quality of life in patients with inflammatory bowel disease: A Spanish multicenter study. Inflamm Bowel Dis 2005;11:488-96.

8. Vergara M, Montserrat A, Casellas F, Villoria A, Suarez D, Maudsley M, et al. A new validation of the Spanish Work Productivity and Activity Impairment Questionnaire-Crohn's disease version. Value Health 2011;14:859-61.

9. Fontanet G, Casellas F, Malagelada JR. La Unidad de Atención Crohn-Colitis: 3 años de actividad. Gac Sanit 2004;18:483-5.

10. Consulta de Enfermería pionera en Galicia. Enfermería avanza, 6 de julio de 2007 (sede web). Disponible en: http://enfeps.blogspot.com/

2007/07/consulta-de-enfermera-pionera-en.html (Acceso 29 de octubre de 2008).

11. Torrejón Herrera A, Masachs Peracaula M, Borruel Sainz N, Castells Carner I, Castillejo Badía N, Malagelada Benaprés JR, et al. Aplicación de un modelo de asistencia continuada en la enfermedad inflamatoria intestinal: la Unidad de Atención Crohn-Colitis. Gastroenterología y Hepatología 2009;32:77-82.

12. Mowat C, Cole A, Windsor A, Ahmad T, Arnott I, Driscoll R, et al. Guidelines for the management of inflammatory bowel disease in adults. Gut 2011;60:571-607.

13. Marín L, Torrejón A, Oltra L, Seoane M, Hernández-Sampelayo P, Vera MI, et al. Nursing resources and responsibilities according to hospital organizational model for management of inflammatory bowel disease in Spain. J Crohns Colitis 2011;5:211-7.

14. Fitch K, Berstein SJ, Aguilar MD, et al. The RAND/UCLA Appropriateness Method User's Manual. Santa Monica: RAND; 2001. Report No. MR-1269-DG-XII/RE.

15. Hernández-Sampelayo P, Seoane M, Oltra L, Marín L, Torrejón A, Vera MI, et al. Contribution of nurses to the quality of care in management of inflammatory bowel disease: A synthesis of the evidence. J Crohns Colitis 2010;4:611-22.

16. IBD Standards Group. "Quality care: Service standards for the healthcare of people who have Inflammatory Bowel Disease (IBD)". The IBD Standards Group, 2009.

17. Shekelle PG, Chassin M, Park RE. Assessing the predictive validity of the RAND/UCLA appropriateness method criteria for performing carotid endarterectomy. Int J Technol Assess Health Care 1998;14:707-27.

18. Shekelle PG, Kahan JP, Bernstein SJ, Leape LL, Kamberg CJ, Park RE. The reproductibility of a method to identify the overuse and under-use of medical procedures. N Engl J Med 1998;338:1888-95.

19. McDonnell J, Meijler A, Kahan JP, Bernstein SJ, Rigter H. Panelist consistency in the assessment of medical appropriateness. Health Policy 1996;37:139-52.

20. Kravitz RL, Laouri M, Kahan JP, Guzy P, Sherman T, Hilborne L, et al. Validity of criteria used for detecting underuse of coronary revascularization. JAMA 1995;274:632-8.

21. Shekelle PG. Are appropriateness criteria ready for use in clinical practice? N Engl J Med 2001;344:677-8.