Journal of Crohn's and Colitis (2010) 4, 611–622

available at www.sciencedirect.com

ScienceDirect

REVIEW ARTICLE

Contribution of nurses to the quality of care in management of inflammatory bowel disease: A synthesis of the evidence

Paloma Hernández-Sampelayo [a], Montserrat Seoane [b], Lorena Oltra [c], Laura Marín [d], Antonio Torrejón [e], María Isabel Vera [f], Valle García [g], Pablo Lázaro [h,*], Elizabeth Parody [h], Antonio J. Blasco [h], Francisco Casellas [e]

[a] *Digestive System Service, Gregorio Marañón University Hospital, C/ Doctor Esquerdo 46, 28007, Madrid, Spain*
[b] *Digestive System Service, Santiago de Compostela University Hospital, C/ la Choupana s/n, 15706, Santiago de Compostela, Coruña, Spain*
[c] *Digestive System Service, Manises Hospital, C/ Las Rosas s/n, 46940, Manises, Valencia, Spain*
[d] *Digestive System Service, Germans Trias i Pujol Hospital, Carretera de Canyet s/n, 08916 Badalona, Barcelona, Spain*
[e] *Digestive System Service, Vall d'Hebron University Hospital, Paseo Vall d'Hebron 119, 08035, Barcelona, Spain*
[f] *Gastroenterology and Hepatology Department, Puerta de Hierro University Hospital, Manuel de Falla 1, 28222 Majadahonda, Madrid, Spain*
[g] *Digestive System Service, Reina Sofía University Hospital, Avenida Menéndez Pidal s/n, 14004, Córdoba, Spain*
[h] *Advanced Techniques in Health Services Research (TAISS), C/ Cambrils 49, 28034, Madrid, Spain*

Received 25 May 2010; received in revised form 13 July 2010; accepted 27 August 2010

KEYWORDS
Quality of care;
Inflammatory bowel disease;
Nurses;
Outcomes;
Systematic review

Abstract

Background: The purpose of quality of care programs is to improve patient outcomes. In programs targeting patients with inflammatory bowel disease (IBD), nurses play a key role.
Aim: To know the available scientific evidence on the quality of care in IBD management, at the levels of structure, process and outcome, in relation to nurses.
Methods: Systematic search in MEDLINE, EMBASE, Índice Médico Español, Cochrane Library, and grey literature. Inclusion criteria were: 1) documents referring IBD; 2) documents providing relevant information on nurses' involvement in the management of IBD; and 3) an original article.
Results: A total of 284 documents were identified, 15 of which were included: 8 related with structure, 12 with process, and 6 with outcomes. Some documents treated more than one level. At the level of structure, services should incorporate specialist nurses as part of the multidisciplinary team, as well as resources to facilitate patient access to nursing care. Notable at the process

* Corresponding author. Tel.: +34 91 7310380; fax: +34 91 7302893.
E-mail addresses: palomasampelayo@gmail.com (P. Hernández-Sampelayo), mseoanefarre@gmail.com (M. Seoane), digestivosagunto@hotmail.com (L. Oltra), lauramarinsan@gmail.com (L. Marín), tonith@gmail.com (A. Torrejón), isabel.vera@supportfactory.net (M.I. Vera), vallegarciasanchez@gmail.com (V. García), plazaro@taiss.com (P. Lázaro), eparody@taiss.com (E. Parody), ablasco@taiss.com (A.J. Blasco), fcasella@vhebron.net (F. Casellas).

1873-9946/$ - see front matter
doi:10.1016/j.crohns.2010.08.009

level, organizational aspects and nurses' competencies and skills in the management of IBD have been described. Among the outcomes mentioned are clinical outcomes, quality of life, and patient satisfaction attributable to nursing staff. No evidence was found about the association between structure or process issues with patient outcomes. Most of the studies reviewed have methodological limitations.

Conclusions: The available evidence provide useful information for the design of standards of structure and process relating to nurses' management of IBD. The IBD nurses' challenge is to provide evidence that these standards help improve health outcomes in patients.

Contents

1. Introduction

Inflammatory bowel disease (IBD) refers to a group of diseases characterized by chronic inflammation of the digestive tract. The two most common of these diseases are ulcerative colitis (UC) and Crohn's disease (CD). IBD mainly affects young people in their productive or formative years and has considerable impact on the quality of life of patients and their families. Among the factors associated with impaired health-related quality of life (HRQoL) in these patients are disease activity,[1–3] time since symptom onset,[2] female gender,[1,2] low educational level[1] and psychological disturbances in the patient.[3] Some 80% of patients report limitations in the ability to have a "normal" social life due to symptoms such as diarrhea, abdominal pain or asthenia. One of every two patients stops carrying out some daily activities due to the clinical manifestations of the disease.[4]

The clinical manifestations of IBD also affect the patients' morale. Most patients feel depressed, discouraged, anxious, angry and powerless due to the symptoms of the disease. Some 70% of patients with IBD who work, especially those with CD, have frequent sick leaves for clinical or psychological reasons.[4]

IBD produces high costs in health systems. Medical and surgical hospitalizations are the main components of direct medical costs.[5] However, indirect costs (loss of productivity due to sick leave) are even higher.[6] For example, in Europe the indirect costs for CD represent 64–69% of total costs.[7] Costs differ considerably depending on disease severity; they are 3 to 9 times higher in patients with severe disease than in those who are in remission.[7] The clinical impact of IBD on HRQoL and its economic impact are growing, since the incidence of the disease is increasing in the developed countries; current incidence is estimated at 9 cases per 100,000 population and year.[8–10]

Given that there is no preventive treatment for IBD, appropriate comprehensive management is required to minimize the problems derived from its clinical, psychological, social and work-related consequences. The key objectives of IBD treatment are to maximize time in remission, produce minimal secondary effects from medication or surgery, alleviate symptoms, resolve complications, and reestablish the patients' quality of life. In the context of quality of care, these objectives could conceptually be considered as outcomes in the process of IBD care. Outcomes can in turn be associated with two other levels of quality of care: structure and process.[11,12]

With regard to structure and process, it has been postulated that to achieve treatment objectives, IBD management requires a multidisciplinary approach in which physicians, nurses, dietitians and social workers interact with one another. In turn, the multidisciplinary approach in IBD management requires certain conditions, for example, specialized health care personnel, adequate infrastructure and equipment, protocols for action, and evaluation of processes, among other aspects that affect health outcomes in patients. Classically, the physician's role in IBD management is well defined, but it would also be useful to define the role of other professionals involved in managing the care of patients with IBD. Among the professionals involved in managing IBD, nurses play an important role. Accordingly, the objective of this study is to know the available scientific evidence on the quality of care in IBD management, at the levels of structure, process and outcome, in relation to nurses.

2. Methodology

2.1. Systematic search

A systematic search of bibliographic databases and the grey literature was performed with regard to management of IBD by nurses.

The search was conducted in the databases MEDLINE, EMBASE, Índice Médico Español (IME), and the Cochrane Plus Library; it was limited to documents published in English or Spanish between January 1999 and September 2009.

The MEDLINE search used the following Medical Subject Headings (MeSH): Inflammatory Bowel Diseases, Chronic disease, Nurses, Nurse's role, Nursing care, Attitude of health personnel, Standards, Quality indicators, and Practice guidelines as topics. To complete the search, other key words in the title and abstract fields were also used: Guidelines, Management, IBD, Quality standard, and Standard of care.

In EMBASE the EMTREE descriptors were used: Enteritis, Chronic disease, Nursing care, Disease management, Standard, and Practice guideline. To complete the search, other key words in the title field were also used: Inflammatory bowel disease and Management.

The terms used to define the search strategies in the IME were obtained from the list of key words included in the database. These are descriptors and synonyms based on MeSH terms from the PubMed system, but adapted to Spanish medical terminology. The descriptors used were: *Crohn*, *Unidad*, *Cuidados*, *Enfermeras*, *Enfermería*, *Manejo* and *Estándares*. In addition to these descriptors, we used other key words that were not indexed: *Enfermedad inflamatoria intestinal*, *Cuidados de enfermería*, *Consulta de enfermería* and *Estándares de calidad*.

In the Cochrane Library the following key words were used: Inflammatory bowel diseases, Nurs*, and Standards.

To conduct the search in the grey literature, we combed the websites of various institutions such as scientific societies and quality of care agencies (Appendix A). A generic search was also performed using the Google search engine, and the first 100 results were reviewed. The search was limited to documents published in English or Spanish.

2.2. Inclusion criteria for documents

The inclusion criteria for consideration in the synthesis of the evidence were that the document must: 1) deal with IBD; 2) provide relevant information on management of the disease involving nursing staff; and 3) be an original article.

2.3. Synthesis of the evidence

The first step was to read the title of each document. If the document was not excluded after reading the title, the abstract was read, and if it was still not excluded, the complete text of the document was read. To decide if the document met the inclusion criteria, two investigators independently reviewed each document, and cases of discrepancy were resolved by consensus. The quality of the evidence for "quantitative" documents was assessed applying the Oxford Centre for Evidence-based Medicine Levels of Evidence,[13] while for articles using "qualitative" research, the Critical Appraisal Skills Programme (CASP) evaluation tool for qualitative research[14] was applied. To assign a level of evidence or to identify potential flaws, two investigators independently reviewed each document, and cases of discrepancy were resolved by consensus.

An evidence table summarizing the synthesis of the evidence was made based on the documents that met the inclusion criteria. The table contains information on: the bibliographic reference (first author, year and reference number), country, objective, study design/methodology, results and conclusions, domain of quality of care treated (structure, process and outcome), level of evidence and comments on the document.

Following the conceptual model of quality of care developed by Donabedian,[11,12] to classify the standards or quality of care indicators found in the selected documents in a specific domain, we used the definitions of structure, process, and outcome of the National Quality Measures Clearinghouse.[15] **Structure** of care, was defined as a *feature of a healthcare organization or clinician relevant to its capacity to provide health care*. For example, facilities, equipment, and nurse/patient ratio are structure-based measures. A **process** of care is a *health care service provided to, on behalf of, or by a patient*. For example, the adherence to explicit recommendations for clinical practice, to provide education and support, or to check the compliance to treatments is a process measure. An **outcome** of care is a *health state of a patient resulting from health care*. For example, outcome measures are mortality, avoided surgery, or improvement in quality of life, among others. To assign a quality domain to each indicator or standard found, two investigators independently classify each indicator, and cases of discrepancy were resolved by consensus.

3. Results

3.1. Documents found in the systematic search

Using the search strategies described, 282 articles were found (50 duplicates) in MEDLINE, 33 in EMBASE, 1 in the IME, and 8 (1 duplicate) in the Cochrane Library. In the search for grey literature, 6 potentially interesting documents were found in the web pages of three organizations: National Association for Colitis and Crohn's Disease (NACC) (2 documents), Society of Gastroenterology Nurses and Associates (SGNA) (1 document), and the IBD Standards Group (3 documents). In the generic search in Google, 6 articles were found in Spanish scientific journals (one was the same as in the IME).

Of the 232 articles in MEDLINE and the 33 in EMBASE, 198 were eliminated after reading the title. The abstracts of 67 articles were read, after which 44 articles were eliminated. Of the 23 articles read, only 10 met the inclusion criteria. Of the 6 articles found in Spanish journals, one was eliminated after reading the abstract; the complete text of the other 5 articles was read, one of which met the inclusion criteria. None of the 7 articles in the Cochrane Plus Library met the inclusion criteria. Accordingly, 11 of the articles identified met the inclusion criteria. With regard to the grey literature, after reading the 6 potentially interesting documents on institutional websites, 4 were found to meet the inclusion criteria. Thus, we found a total of 15 documents dealing with

Table 1 Synthesis of the evidence.

Reference/country	Objective(s)	Design/methodology	Results and conclusions	Aspect treated	Level of evidence [a]/comments
Nightingale et al.[16] England	To determine the effect of a specialist nurse on outcomes in patients with IBD.	Intervention study (before–after). Audit of management of a cohort of 339 patients in the year before and after employment of an IBD specialist nurse. Patients received educational material on lifestyles, health promotion, medications and diagnostic tests. Direct telephone access to the specialist nurse was established. The outcome variables were: patient's health status, number of consultations, hospital admissions, length of stay, quality of life, and satisfaction with service.	Hospital visits were reduced by 38% and length of hospital stay by 19%. The number of patients in remission increased from 63% to 69%. Quality of life was unchanged. Patient satisfaction improved with regard to access to information on IBD, advice on avoidance of illness and maintaining health. Of the 251 calls to the telephone helpline, only 19 patients were referred for a medical opinion and 5 patients required hospital admission. The IBD specialist nurse is a valuable and cost-effective member of the gastroenterology team in terms of improved patient education and satisfaction and disease management.	S, O	4 Sample size is not specified, nor is information provided on the statistical analysis. No details are given on the cost-effectiveness analysis. Given these limitations, the results should be considered with caution.
Smith et al.[17] United Kingdom	To demonstrate that nurse-led psychological counseling improves health-related quality of life (HRQoL) in patients with IBD.	Randomized controlled trial including 100 patients with IBD. Physical and psychological wellbeing were assessed using the SF-36 questionnaire. The intervention consisted of providing orientation and information to half the patients by a trained nurse. HRQoL was assessed at baseline, 6 months and 12 months. Anxiety and depression were assessed using the Hospital Anxiety and Depression (HAD) questionnaire.	The intervention produced improvement in the SF-36 mental health domain in patients with Crohn's disease (but not in ulcerative colitis) at 6 months, but not at 12 months. There was no difference in the SF-36 physical health domain. No differences were observed in HAD scores or in adaptive styles.	O	2b Lack of sufficient statistical power (small sample size). Possible bias in patient selection. Inappropriate statistical analysis. Due to methodological limitations, the results should be considered with caution.
Leshem[18] Israel	To discuss the importance of support groups for patients with IBD and to describe the role of gastroenterology nurses in these groups.	Opinion article	Nurses have an important role in the formation and coordination of support groups for IBD patients. Assessment of outcomes with regard to quality of life, wellbeing, and levels of stress and anxiety in participating	P	5 The search methodology, in which the opinions are based, is not specified.

			patients is recommended. Nurses often have the knowledge, experience and abilities needed to organize support groups for patients with IBD.		
Cónsul and Soldevilla[19] Spain	To provide a review of IBD via a real case.	Opinion article about a case of IBD in a nurse	Nursing units must confront psycho-social aspects like isolation, shame, fear, distress, and myths, among other aspects involved in all chronic diseases affecting the patient's personal, family and social life. Education and support are essential elements in palliating these aspects.	P	5 Experience of one case. The article is illustrative, but cannot be generalized.
van der Eijk et al.[20] Norway, Denmark, Holland, Ireland, Portugal, Italy, Greece, Israel	To compare European health care facilities and to define "best practice" in IBD management.	Observational study (audit) conducted at 8 university hospitals and 4 general hospitals using a questionnaire to evaluate 20 characteristics of the facility. Consensus was reached with regard to defining current "best practice."	"Best practice" related to nursing care includes: availability of daily telephone consultation, records of both treating physician and paramedics in the same patient file, protocols provided to doctors and nurses, continuous postgraduate training, wide integration, and rotation of nurses in outpatient, inpatient, and endoscopy units.	P	2c The article also mentions other non-specific nursing standards.
Pearson[21] England	Not stated. A reading of the article suggests that the objective is the implementation of a telephone helpline for patients directed by the specialist nurse.	Observational study (before–after) including 825 patients. Study duration: 24 months. In addition, qualitative methodology was used (survey, focus groups and process mapping).	The first phase of the audit reflected lack of a standardized focus for monitoring immunosuppressors. The focus groups showed a high level of satisfaction with the IBD service with regard to emotional and psychological support and information received. Responsibilities identified in the methodology: the nurses are responsible for a telephone helpline, coordinating hematological monitoring and control of follow-up visits. The side effects of medications were detected earlier (21 days on average).	S, P, O	4 The study design is not clear, the objectives are not stated, and methodological details are lacking (e.g., sample size and statistical analysis). The qualitative research has several weaknesses: details of questionnaire (structure and reliability), focus group (interviews recording, transcription, and reliability measures), and process mapping (framework) not reported.

(continued on next page)

Table 1 (*continued*)

Reference/country	Objective(s)	Design/methodology	Results and conclusions	Aspect treated	Level of evidence [a]/comments
Gray[22] United Kingdom	To identify the most important aspects of the health services and those that should be improved, according to IBD patients and their caregivers.	Qualitative. Two focus groups, one for IBD patients and the other for caregivers.	Specialist nurses should be part of the multidisciplinary team for IBD management. They are essential as the point of contact between patients and health personnel.	S, P	Qualitative research. Details are lacking on the focus group recruitment, number and profiles of participants, and analysis, among other potential sources of bias.
SGNA[23] United Kingdom	Development of quality standards of clinical nursing practice in gastroenterology.	Development of quality standards. Based on the standards of the American Nursing Association. Delineation of the role of nurses was obtained from the SGNA document.	Describes 16 functions to be carried out by specialist nurses. Nurses must evaluate their own professional practice, establish priorities and make ethically-sound decisions, collaborate with other health professionals, manage follow-up of patient care and respond to emergency situations to ensure optimal outcomes by recognizing changes in patients' health status.	P	5 The target group for the standards is specified, but they do not explain how they were developed (e.g., if by Delphi, consensus of experts…).
Pearson[24] England	Not stated. A reading of the article suggests that the objective is the implementation of a telephone helpline for patients directed by the specialist nurse.	Observational study (before–after). The database included 756 patients with IBD. A nurse-led telephone helpline was established. In addition, qualitative methodology was used: patient questionnaire, focus groups and discussion groups were used.	In 12 months the nurse conducted 950 follow-ups. Implementation of the helpline made it possible to: free up time for the specialist, improve communication within the team, and reduce hospital stay by 4 days and time of detection of side effects by 21 days. Responsibilities identified in the methodology: being available so that patients with flare-ups have someone to contact, make periodic calls to stable patients, ensure that patients come for routine and preventive examinations, verify compliance with treatment, early detection of adverse effects, and participation in the administration of biologic treatments.	S, P, O	4 Objectives not stated, no clear study design, lack of details on the methodology used, no statistical analysis applied, and sample size not explained. Qualitative research methodology is not described. Data to support the findings are not presented.

Cierzniakowska et al.[25] Poland	To present some problems relating with the IBD patient in the perisurgical period.	Opinion article	The authors present problems that may arise when IBD patients receive surgery. They indicate how nurses should act when faced with these problems and what would be the expected effects.	P	5 The conclusions are not related with the results.
Belling et al.[26] United Kingdom	Not stated. A reading of the article suggests that the objective is to know the perceptions of stakeholders (mainly patients and family members) about ideal behaviors and personal characteristics of IBD specialist nurses.	Qualitative (thematic focus). 131 participants: most are patients and relatives of patients.	The skills and behaviors highlighted by participants are related with easy availability of specialized nurses. The most frequently mentioned personal characteristics were: kindness, empathy, and ability to give patients the confidence to cope with their disease. A wide range of behaviors, skills and personal attributes of IBD specialist nurses mark the difference in patient care.	P	Qualitative research. The aim of the research is not clearly stated, and details on the profile of respondents and analysis are not specified.
Jones et al.[27] England	To develop quality criteria for the management of four gastrointestinal disorders: celiac disease, gastro-esophageal reflux disease, IBD and irritable bowel syndrome.	Qualitative study including 3 patient focus groups on IBD. Additionally, a literature review and guideline synthesis, and quality criteria setting process were done (not included in this review).	Patients should have access to IBD specialist nurse, practice nurse, and stoma nurse.	S	Qualitative research. Details are lacking on the focus group recruitment, number and profiles of participants, and analysis. Data to support the findings are not presented.
IBD Standards Group[28] United Kingdom	To describe the standards to ensure that IBD patients receive high quality care.	Document referring to quality standards. The document is a report of the National Health Service (NHS) and is part of a strategy in the United Kingdom to improve services and care to patients with IBD. The results are based on the audit report of the United Kingdom IBD group.	An IBD unit that serves a population of 250,000 should have 1.5 IBD specialist nurses and 1.5 specialist nurses in ostomies and ileoanal surgery. Among the quality standards is that patients should have rapid access to clinical counseling from specialist nurses (mainly when they have flare-ups), ideally by telephone or email, and that nurses should participate in meetings of the multidisciplinary team.	S, P	5 The document also describes other IBD management standards not specific to nursing.

(continued on next page)

Table 1 (*continued*)

Reference/country	Objective(s)	Design/methodology	Results and conclusions	Aspect treated	Level of evidence[a]/comments
UK IBD Audit Steering Group[29] United Kingdom	To audit IBD Services in the United Kingdom to determine if they meet quality standards and to assure that patients receive high quality care.	Observational study to assess the level of compliance with the quality standards of the IBD Standards Group. Data collection was done online via the website. The audit was conducted between September and December 2008.	The number of IBD specialist nurses has increased in recent years, however 38% of the sites do not yet have an IBD specialist nurse. The time that specialist nurses devote to IBD care has also increased. The study demonstrates the need to increase the number of specialist nurses to the level recommended by the IBD Standards Group.[28] Access to telephone contact with an IBD specialist nurse is available in 85% of sites and email contact is available in 41% of sites.	S, P, O	2c The report presents the main findings and recommendations for each standard.
Ludlow et al.[30] United Kingdom	To investigate whether the use of email and text messaging helps to improve services offered to patients and reduce delays in blood tests.	Intervention study (before–after) including 126 patients with IBD being treated with azathioprine or mercaptupurine. Patients were divided into three groups (self-selection): reminder of blood test by email, reminder of blood test by text message, and a control group that received telephone calls and occasional letters. Analysis of information and days that monitoring tests were delayed. The IBD nurse was responsible for follow-up.	There was overall improvement in all three groups in the number of days of delay and in the number of important delays (over 28 days), although the email and text messaging groups had fewer delays than the control group. Patients in the email and text messaging groups found these methods of contact to be useful for follow-up and wished them to continue. The authors conclude that the intervention is cost-effective.	S, P, O	4 A limitation described in the study is that it was not random, thus it is subject to several sources of bias. Other study limitations are lack of methodological detail (e.g., they do not specify the statistical analysis and there is no analysis of cost-effectiveness) and lack of detailed results. For these reasons, the results should be considered with caution.

S: structure; P: process; O: outcomes.

[a] Levels of evidence according to the Oxford Centre for Evidence-based Medicine Levels of Evidence.[13] For qualitative research articles, the CASP tool was used for assess the methodological quality.[14]

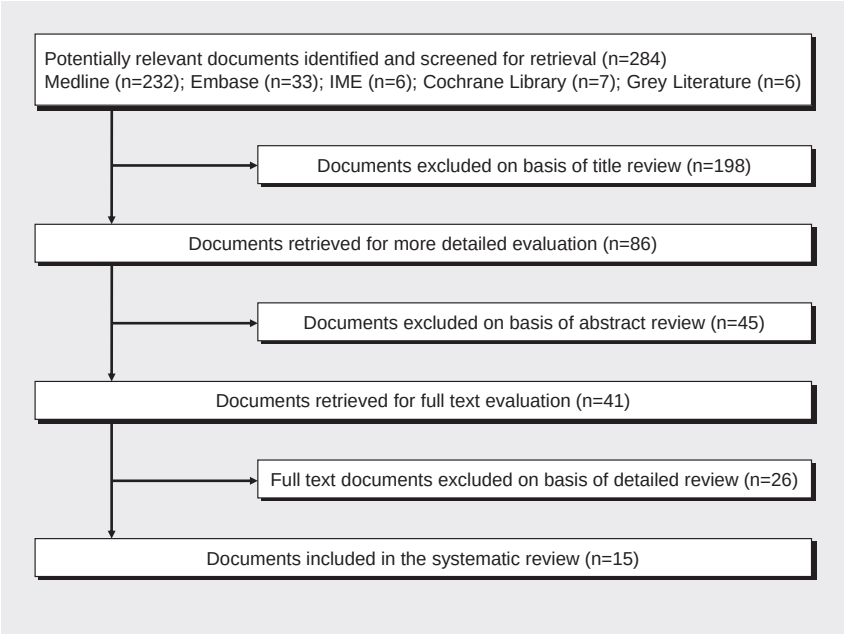

Figure 1 Flow of document selection.

IBD that provide relevant information on disease management by nurses[16–30] (Table 1). Fig. 1 summarizes the flow of document search.

3.2. Synthesis of the evidence

With regard to study design or methodology, 5 studies use qualitative methodology,[21,22,24,26,27] 4 are observational studies,[20,21,24,29] 2 are intervention studies,[16,30] 2 refer to quality standards,[23,28] 3 are opinion articles,[18,19,25] and one is a randomized controlled clinical trial.[17] Two documents[21,24] use more than one methodology.

Eight documents were found to be related with the "structure" of the service[16,21,22,24,27–30]; 12 with "process," such as organizational aspects of the service related with nurses' management of IBD,[20,29] skills of nursing staff in IBD management,[19,21–25,28,30] skills that nursing staff should have in managing IBD,[18,26] and 6 documents were related with clinical and quality of life "outcomes" in patients attributable to the role of nurses.[16,17,21,24,29,30] Some documents treated more than one domain.

No conceptual or operational definition was found of organized forms of nursing (e.g., nursing units) for the management of IBD.

The IBD Standards Group establishes that an IBD unit (IBDU) covering a population of 250,000 should have 1.5 IBD specialist nurses and 1.5 specialist nurses in ostomies and ileoanal surgery.[28] However, in a study carried out in the United Kingdom, 79 of 207 centers surveyed (38%) did not have specialist nurses.[29] The study also showed that, although patients should have telephone or email access to specialist nurses for medical advice, patients do not have telephone access in 15% of centers, and do not have email access in 59%.[29]

In terms of process, among other quality standards, nurses should participate in meetings of the IBD unit and should rotate to inpatient, outpatient and endoscopy units to improve their knowledge.[20] Numerous skills, both conceptual and operational, were assigned to nurses in IBD management. Notable among these are integration within the multidisciplinary team,[22,28] acting as a link between the patient and the team and with primary care,[22] compliance with treatment,[24] early identification of adverse effects,[21,24] provision of health information to patients and their families,[16,17] provision of emotional support,[17,19] being accessible when the patient so requires[27,28] (for example, giving advice by telephone[16,21,24,28,29]), and organizing patient support groups by selecting group participants, establishing objectives and looking for subjects of interest.[18]

The attributes of nurses most highly valued by patients and their families include easy availability, kindness, empathy, and the ability to communicate and to reinforce patients' confidence.[26]

Only 5 original studies (4 observational[16,21,24,30] and one controlled clinical trial[17]) measure patient outcomes attributable to nursing interventions. Among these outcomes, the authors refer to: a) improved mental domain on the SF-36 quality of life questionnaire in patients with CD (but not UC) at 6 months, but not at 12 months,[17] whereas others do not find quality of life differences[16]; b) reduced number of hospital visits[16] and reduced length of hospital stay[16,24]; c) increased patient satisfaction[21]; d) earlier detection of adverse effects[21,24]; e) increased number of patients in remission[16]; and f) reduced working time of the specialist physician.[24]

From the methodological point of view, these found quantitative studies have important limitations, such as design defects, lack of statistical analysis, inappropriate analysis, and numerous sources of bias. According to the Oxford Centre for Evidence-based Medicine Levels of Evidence, the maximum

level of evidence reached by an article in our review is 2b. The qualitative research studies have also several flaws which make them vulnerable to bias (see Table 1, "Level of Evidence/ Comments").

4. Discussion

This review provides a synthesis of the available evidence on relevant aspects of the quality of care in nurses' management of IBD. These aspects have been classified into three large subject areas: structure, process and outcomes. Some of the documents found treat one or more of these aspects.

With adequate structural elements, such as personnel and medical and physical resources, the process of care could be said to be the key element in assuring quality. In these conditions, an adequate "process" of care has a high probability of producing a satisfactory outcome in providing the service, thus "process" is a key element of quality, whose ultimate objective is to improve patient outcomes.[11,12] The documents reviewed that deal with structure highlight the importance of having an IBD specialist nurse for a specified number of inhabitants. The availability of telephone access for patients receiving care from an IBD nurse is reported to be associated with beneficial patient outcomes.[16,21,24]

Health care, considered as a comprehensive process, could help to improve continuity in patient care, so that coordination and integration among the different levels of care guarantee consistent, appropriate, and high quality health care. In this continuity of care, some of the studies reviewed consider nursing personnel as the link between specialized care and primary care and as key persons in assuring that patients have easier access to other health professionals.

IBD requires a multidisciplinary approach. The scientific literature shows the important role that nurses have in managing this disease and in providing patients with education, counseling, and physical and emotional support, among other aspects. In fact, patients with IBD evaluate positively the role of nurses in disease management and emphasize the confidence and peace of mind they have in being treated by nurses.

Unfortunately, the studies found have important methodological limitations, especially those that try to identify associations between the role of nurses and patient outcomes (some do not state their objectives, do not describe how patients are selected, or use inappropriate statistical analyses, among other limitations). Our assessment of the methodological quality of the found evidence is consistent with the assessment done in two previous systematic reviews of the effectiveness of inflammatory bowel disease specialist nurses,[31,32] and one non-systematic review on the contribution of specialist nurses in managing patients with IBD.[33] Consequently, the results of the available studies must be viewed with caution.

The standards of structure and process found were few, highly variable, and the underlying logic of their development is poorly documented. For these reasons, it would be advisable to design standards of structure and process dealing with organized forms of IBD care by nurses as an important part of the multidisciplinary team of professionals who manage IBD.

The hypothesis that organized forms of nursing care in IBD, with explicit responsibilities and integration of nurses within the team, will improve patient outcomes is plausible. But this hypothesis has not been verified in the present review. Methodologically sound studies should be designed to confirm this hypothesis. The challenge for IBD nurses is to produce the needed evidence, to demonstrate the relevance of their role in caring IBD patients.

Naturally there are other conceptual models of quality of care different from what was used in this work. But they all share the common aim of improving patient outcomes.[34–36] An outcome measure can be used to assess quality of care to the extent that health care services influence the likelihood of desired health outcomes,[15] but based on the scientific evidence available from our review, we do not know the degree to which nurses help bring patients' health outcomes closer to the desired outcomes. Thus, IBD nurses have an excellent opportunity to produce knowledge on the most appropriate ways to improve patient outcomes as a function of different models of organizational processes and structures of nurses' management of IBD.

In conclusion, despite the methodological limitations of the studies reviewed, the documents found provide information that could serve as a foundation for the design of standards of structure and process for the management of IBD by nurses. The next step would be to demonstrate that these standards help improve desired health outcomes in patients. These two steps will require the design and implementation of research projects aimed at covering the gaps in knowledge that have been detected, specially the association between nursing interventions and patient outcomes.

Acknowledgements

The authors acknowledge Abbott Laboratories for funding the study. Abbott Laboratories has not participated in any part of the study.

Contribution of each author: FC participated in the design of the study, provided significant advice along the study, and contributed to data interpretation; PHS participated in the design of the study, provided significant advice along the study, and contributed to data interpretation; MS participated in the design of the study, provided significant advice along the study, and contributed to data interpretation; LO participated in the design of the study, provided significant advice along the study, and contributed to data interpretation; LM participated in the design of the study, provided significant advice along the study, and contributed to data interpretation; AT participated in the design of the study, provided significant advice along the study, and contributed to data interpretation; MIV participated in the design of the study, provided significant advice along the study, and contributed to data interpretation; VG participated in the design of the study, provided significant advice along the study, and contributed to data interpretation; PL participated in the design of the study, designed the literature search, contributed to data synthesis and interpretation, and drafted the manuscript; EP participated in the design of the study, designed the literature search, contributed to data synthesis and interpretation, and drafted the manuscript; and AJB participated in the design of the study, designed the

literature search, contributed to data synthesis and interpretation, and drafted the manuscript. All authors read and approved the final manuscript.

Appendix A. National organizations

- Asociación de Enfermos de Crohn y Colitis Ulcerosa (ACCU) [www.accuesp.com]
- Asociación Española de Gastroenterología (AEG) [www.aegastro.es]
- Associaçao Brasileira de Colite Ulcerativa e Doença de Crohn (ABCD) [www.abcd.org.br]
- Associaçao Portuguesa de Doença Inflamatória do Intestino (APDI) [www.apdi.org.pt]
- Association François Aupetit (AFA) [www.afa.asso.fr]
- Association Luxembourgeoise de la Maladie de Crohn (ALMC)
- Australian Crohn's & Colitis Association [www.crohnsandcolitis.com.au]
- Australian Crohn's & Colitis Association (Queensland) [www.accaq.org.au]
- British Society of Gastroenterology (BSG) [www.bsg.org.uk]
- Canadian Society of Gastroenterology Nurses & Associates [www.csgna.com]
- Colitis Crohn Foreningen (CCF) [www.ccf.dk]
- Crohn en Colitis Ulcerosa Vereniging Nederland (CCUVN) [www.crohn-colitis.nl]
- Crohn en Colitis Ulcerosa Vereniging vzw (CCV) [www.ccv-vzw.be]
- Crohn Club (VUV) — Vyskumny úústav vyzivy
- Crohn's and Colitis Association in Finland [www.crohnjacolitis.fi]
- Crohn's and Colitis Foundation of America (CCFA) [www.ccfa.org]
- Crohn's and Colitis Foundation of Canada (CCFC) [www.ccfc.ca]
- Deutsche Morbus Crohn/Colitis Ulcerosa Vereinigung (DCCV e. V.) [www.dccv.de]
- Federazione Nazionale delle Associazione per le Malattie Inflammatorie Croniche dell'Intestino (AMICI) [www.amiciitalia.net]
- Grupo Andaluz para el Estudio de la Enfermedad Inflamatoria Intestinal (GAEEII) [www.a2000.es/gaeeii]
- Grupo Español de Trabajo en Enfermedad de Crohn y Colitis Ulcerosa (GETECCU) [www.geteccu.org]
- Irish Society for Colitis & Crohn's Disease (ISCC) [www.iscc.ie]
- Israel Foundation for Crohn's Disease and Ulcerative Colitis
- Landsforeningen Mot Fordoyelsessykdommer (LMF) [www.lmfnorge.no]
- Magyarországi Crohn-Coliteses Betegek Egyesülete (MCCBE) [www.mccbe.hu]
- National Association for Colitis and Crohn's Disease (NACC) [www.nacc.org.uk]
- Österreichische Morbus Crohn-Colitis Ulcerosa Vereinigung (ÖMCCV) [www.oemccv.at]
- Riksförbundet föör Mag-och Tarmsjuka (RMT) [www.magotarm.se]
- Schweizerische Morbus Crohn/Colitis Ulcerosa Vereinigung (SMCCV) [www.smccv.ch]
- Sociedad Española de Patología Digestiva (SEPD) [www.sepd.es]
- Society of Gastroenterology Nurses and Associates (SGNA) [www.sgna.org]
- South African Crohn's & Colitis Association
- Swiss Association of Crohn's Disease/Ulcerative Colitis [www.smccv.ch]
- Zimbabwe Association for Colitis & Crohn's Disease

International organizations

- International Foundation for Functional Gastrointestinal Disorders [www.iffgd.org]
- European Crohn's and Colitis Organisation (ECCO) [www.ecco-ibd.eu]
- European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA) [www.efcca.org]

Institutions that develop quality standards or indicators of process

- The IBD Standards Group [www.ibdstandards.org.uk]
- National Quality Measures Clearinghouse (NQMC) [www.qualitymeasures.ahrq.gov]
- National Guidelines Clearinghouse (NGC) [www.guidelines.gov]
- Northwestern Inflammatory Bowel Disease Center [www.ibdcenter.org]
- Royal College of Nursing (Crohn's and Colitis Special Interest Group) [www.ibdnurses.com]
- Unidad de Atención Crohn-Colitis (UACC) [www.ua-cc.org]
- University of Chicago Inflammatory Bowel Disease Center [www.ibdcenter.uchicago.edu]
- National quality of care agencies in different countries (e.g., NICE in the United Kingdom) and international institutions (e.g., WHO and INHATA)

References

1. Casellas F, López-Vivancos J, Casado A, Malagelada JR. Factors affecting health related quality of life of patients with inflammatory bowel disease. *Qual Life Res* 2002;**11**:775–81.
2. 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.
3. Vidal A, Gómez-Gil E, Sans M, Portella MJ, Salamero M, Piqué JM, et al. Health-related quality of life in inflammatory bowel disease patients: the role of psychopathology and personality. *Inflamm Bowel Dis* 2008;**14**:977–83.
4. Estudio Prospectivo Delphi. Costes sociales y económicos de la enfermedad inflamatoria intestinal (Colitis Ulcerosa y Enfermedad de Crohn). FAES Farma; 2005 (Accessed January 4, 2010, at: http://www.faes.es/homepage_intro.html).
5. Odes S, Vardi H, Friger M, Wolters F, Russel MG, Riis L, et al. European Collaborative Study on Inflammatory Bowel Disease. Cost analysis and cost determinants in a European inflammatory bowel disease inception cohort with 10 years of follow-up evaluation. *Gastroenterology* 2006;**131**:719–28.
6. Juan J, Estiarte R, Colomé E, Artés M, Jiménez FJ, Alonso J. Burden of illness of Crohn's disease in Spain. *Dig Liver Dis* 2003;**35**:853–61.

7. Yu AP, Cabanilla LA, Wu EQ, Mulani PM, Chao J. The costs of Crohn's disease in the United States and other Western countries: a systematic review. *Curr Med Res Opin* 2008;**24**:319–28.
8. 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.
9. 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.
10. Saro C, de la Coba C, Lacort M, González A, Álvarez A, Pérez-Pariente JM, et al. Changes in incidence of inflammatory bowel disease during the last 15 years: a epidemiological prospective population-based study from Gijón (Spain) (1992–2006). *Gut* 2007;**39**(Suppl 1):A129.
11. Donabedian A. The quality of care. *JAMA* 1988;**260**:1743–8.
12. Donabedian A. Evaluating the quality of medical care. *Milbank Q* 2005;**83**:691–729.
13. Oxford Centre for Evidence-based Medicine Levels of Evidence. http://www.cebm.net/index.aspx?o=1025March 2009 Accessed November 8, 2009, at:.
14. Critical Appraisal Skills Programme (CASP). Making sense of evidence. 10 questions to help you make sense of qualitative research. (Accessed November 8, 2009, at: http://www.phru.nhs.uk/Doc_Links/Qualitative%20Appraisal%20Tool.pdf).
15. The National Quality Measures Clearinghouse. Using measures. (Accessed November 10, 2009, at: http://www.qualitymeasures.ahrq.gov/resources/measure_use.aspx).
16. Nightingale AJ, Middleton W, Middleton SJ, Hunter JO. Evaluation of the effectiveness of a specialist nurse in the management of inflammatory bowel disease (IBD). *Eur J Gastroenterol Hepatol* 2000;**12**:967–73.
17. Smith GD, Watson R, Roger D, McRorie E, Hurst N, Luman W, et al. Impact of a nurse-led counseling service on quality of life in patients with inflammatory bowel disease. *J Adv Nurs* 2002;**38**:152–60.
18. Leshem RN. Inflammatory bowel disease support groups: a primer for gastroenterology nurses. *Gastroenterol Nurs* 2003;**26**:246–50.
19. Cónsul M, Soldevilla M. La enfermedad inflamatoria intestinal: reflexiones sobre los cuidados de enfermería a partir de un caso. *Nursing* 2004;**22**:58–64.
20. van der Eijk I, Verheggen FW, Russel MG, Buckley M, Katsanos K, Munkholm P, et al. European Collaborative Study Group on Inflammatory Bowel Disease (EC-IBD). "Best practice" in inflammatory bowel disease: an international survey and audit. *Eur J Intern Med* 2004;**15**:113–20.
21. Pearson C. A nurse-led IBD service in a district general hospital. *Gastrointest Nurs* 2005;**3**:33–9.
22. Gray J. Improving standards of care for colitis and Crohn's disease (NACC). A report of two patient focus groups run by NACC in 2004/5. National Association for Colitis and Crohn's Disease (NACC); 2005 (Accessed November 3, 2009, at: http://www.nacc.org.uk/downloads/research/2005/gray.pdf).
23. Standards of clinical nursing practice and role delineation statements. Society of Gastroenterology Nurses and Associates (SGNA); 2005 (Accessed November 6, 2009, at: http://www.sgna.org/Resources/RoleDelineationsfinal1004.pdf).
24. Pearson C. Establishing an inflammatory bowel disease service. *Nurs Times* 2006;**102**:28–9.
25. Cierzniakowska K, Szewczyk MT, Cwajda J. Inflammatory bowel disease — nursing care during the surgery treatment period. *Adv Med Sci* 2007;**52**(Suppl 1):64–77.
26. Belling R, Woods L, McLaren S. Stakeholder perceptions of specialist inflammatory bowel disease nurses' role and personal attributes. *Int J Nurs Pract* 2008;**14**:67–73.
27. Jones R, Hunt C, Stevens R, Dalrymple J, Driscoll R, Sleet S, et al. Management of common gastrointestinal disorders: quality criteria based on patients' views and practice guidelines. *Br J Gen Pract*
28. IBD Standards Group. Quality care: service standards for the healthcare of people who have inflammatory bowel disease (IBD). IBD Standards Group; 2009 (Accessed November 12, 2009, at: http://www.ibdstandards.org.uk/uploaded_files/IBDstandards.pdf).
29. UK IBD Audit Steering Group. UK IBD Audit 2nd Round (2008) Report: national results for the organisation & process of adult IBD care in the UK. Generic hospital report. The UK IBD Audit Steering Group; 2009 (Accessed November 11, 2009, at: http://www.rcplondon.ac.uk/clinical-standards/ceeu/Current-work/Documents/UK-IBD-Audit-2nd-Round-Full-National-Report-Appendices.pdf).
30. Ludlow H, Hurley J, Dolwani S. Using email and text messaging to remind patients to have blood monitoring test. *Nurs Times* 2009;**105**(28):26–8.
31. Woods L, Belling R, McLaren S. A systematic review of the effectiveness of inflammatory bowel disease specialist nurses. Final report. National Association for Colitis and Crohn's Disease (NACC); 2006 (Accessed November 5, 2009, at: http://www.nacc.org.uk/downloads/NACC_Systemeatic_Review_IBD_Nursing_Dec2006.pdf).
32. Belling R, McLaren S, Woods L. Specialist nursing interventions for inflammatory bowel disease. *Cochrane Database Syst Rev* 2009, doi:10.1002/14651858.CD006597.pub2 Issue 4. Art. No.: CD006597.
33. Younge L, Norton C. Contribution of specialist nurses in managing patients with IBD. *Br J Nurs* 2007;**16**:208–12.
34. Berwick DM. A user's manual for the IOM's 'Quality Chasm' report. *Health Aff* 2002;**21**(3):80–90.
35. Institute of Medicine, Committee to Design a Strategy for Quality Review and Assurance in Medicine. Lohr KN, editors. Medicare: a strategy for quality assurance. Committee to Design a Strategy for Quality Review and Assurance in Medicare, Division of Health Care Services, Institute of Medicine. Vol. 1, Report of a study. Washington (DC): National Academy Press; 1990.
36. The National Quality Measures Clearinghouse. Using measures. (Accessed March 18, 2010, at: http://www.qualitymeasures.ahrq.gov/resources/measure_use.aspx).