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BRIEF ARTICLE

Framework for assessing quality of care for inflammatory bowel disease in Sweden

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Abstract

AIM: To create and apply a framework for quality assessment and improvement in care for inflammatory bowel disease (IBD) patients.

METHODS A framework for quality assessment and improvement was created for IBD based on two generally acknowledged quality models. The model of Donabedian (Df) offers a logistical and productive perspective and the Clinical Value Compass (CVC) model adds a management and service perspective. The framework creates a pedagogical tool to understand the balance between the dimensions of clinical care (CVC) and the components of clinical outcome (Df). The merged models create a framework of the care process dimensions as a whole, reflecting important parts of the IBD care delivery system in a local setting. Clinical and organizational quality measures were adopted from clinical experience and the literature and were integrated into the framework. Data were collected at the yearly check-up for 481 IBD patients during 2008. The application of the quality assessment framework was tested and evaluated in a local clinical IBD care setting in Jönköping County, Sweden.

RESULTS: The main outcome was the presentation of how locally-selected clinical quality measures, integrated into two complementary models to develop a framework, could be instrumental in assessing the quality of care delivered to patients with IBD. The selected quality measures of the framework noted less anemia in the population than previously reported, provided information about hospitalization rates and the few surgical procedures reported, and noted good access to the clinic.

CONCLUSION: The applied local quality framework was feasible and useful for assessing the quality of care delivered to IBD patients in a local setting.

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Key words: Quality measures; Inflammatory bowel disease; Value compass; Donabedian; Quality improvement

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INTRODUCTION

In modern healthcare, there is often a gap between the expected level of healthcare delivery and the actual healthcare provided, as shown by McGlynn *et al*[1]. This is also true for the care of inflammatory bowel disease (IBD), as highlighted recently in an editorial by Siegel[2] and previously by Reddy *et al*[3] as well as by the American Gastroenterology Association[4] several years ago. There is still no framework or general quality measures for IBD as noted by Kappelman[5], who called for action and challenged the gastroenterology community to correct this.

IBD is a chronic disease with two primary subtypes; Crohn's disease (CD), and ulcerative colitis (UC)[6]. The incidence of CD and UC in Sweden is approximately 6 and 15 per 100 000 inhabitants, respectively, and the prevalence is approximately 150 and 300 per 100 000, respectively[7]. Because of the early age at onset and the absence of curative treatment, the vast majority of patients require lifelong medical care, which periodically leads to intensive outpatient contact, hospitalizations, and occasionally surgery. Improved quality of care aims to minimize the symptoms of the disease, improve quality of life, and meet the goal of delivering the best possible value of care to the patient[8]. These targets are well captured in the Institute of Medicine's mnemonic, stressing the need for safe, timely, efficient, evidence-based, effective, and patient-centered care (STEEEP)[9].

During the first years of the new millennium, the structure of care for IBD patients within the Gastroenterology Unit at the Department of Internal Medicine, Highland Hospital, Eksjö, Sweden was significantly redesigned as previously reported[10,11]. Along with the redesign, the need to be able to monitor the changes and the quality of care became obvious. Obvious also was the absence of any known framework and quality measures for the assessment of quality of care for IBD. To bridge this gap, a selection of clinical and organizational parameters were integrated into two generally acknowledged quality models adopted from Donabedian (Df)[12] and the Clinical Value Compass (CVC)[13], and were merged to form a quality framework. The collection of quality measures was accomplished as a part of the ordinary yearly check performed by a specialist nurse or by a gastroenterologist. The selected measures were integrated and applied to the quality framework as a means to assess the quality of IBD care in the local setting.

A quality assessment tool may be developed in several ways, and there are several critical steps when creating a quality framework; these include design, implementation, and utilization. Each of these factors must be addressed before the framework can be used. Furthermore, before the process of introducing a framework begins, insight into the complexity of care, an understanding of the systems used, and sound professional knowledge, all coupled with both enthusiasm and leadership, are required[8,14,15].

In this study, two generally acknowledged quality models were used. The first, according to Df[12], has been discussed previously by Kappelman *et al*[5] and testing on IBD care was suggested. Donabedian advises that the following questions are to be asked before using a quality framework[12]: "who and what activities are to be assessed"; "how are these activities supposed to be conducted"; and "what are they to accomplish?" These are all important questions to raise and are possible to apply to health care institutions. The model according to Donabedian derives the quality of care from the components of structure, process, and outcome. Structure denotes the attributes of the setting and includes the facilities, equipment, human resources, and organizational structure. Processes are defined by what is actually done in delivering and receiving care. Furthermore, outcome denotes the effects of care on the health status of patients and populations, conveys a production management perspective, and frames a delivery-focused approach by the organization.

The second model is the CVC[13]. It was derived from a management customer area, and offers a flexible framework where the outcomes of health care are perceived in four dimensions as follows: (1) functional; (2) economic; (3) satisfaction with health care; and (4) clinical outcome. The use of already existing measures is favored to avoid add-on routines, making it possible to fulfill the intertwined assignment to both manage the patient and improve care by measuring outcomes[16].

The Df offers a logistical, productive perspective to the studied case, and the CVC adds a management and service perspective. The framework creates a pedagogical tool to understand the balance between the dimensions of clinical care (CVC) and the components of clinical outcome (Df). Together they create a framework of the care process dimensions as a whole, reflecting important parts of the IBD care delivery system in a local setting.

Quality measures are valuable means of improving clinical practice. The use of quality measures may be defined as the process of collecting, computing, and presenting quantified constructs for the managerial purposes of following up, monitoring, and improving organizational performance[17]. The basis of this argument is that they play a significant role in the coordination of organizational activity[18], decision-making, prioritization[19], comparisons, and initiation of improvement processes[20]. In every effort to measure the performance, it is important to consider the desired application of the information obtained. The application of the information may be to control, budget, motivate, or improve the care[21]. As part of the explorative case study, well established measures such as hemoglobin, quality of life, medication, and

access to care, which were practical to perform and used in daily clinical life, were chosen after a review of relevant literature and from clinical experience[22-24].

The aim of this study was two fold; firstly, to apply a generally acknowledged quality framework to the assessment and improvement of care for IBD, and secondly, to study and evaluate its application in a local clinical IBD care setting in Jönköping County, Sweden.

MATERIALS AND METHODS

The measures in this study originate from the Gastroenterological Unit responsible for all IBD care in the area, which is a part of the Department of Internal Medicine at the Highland Hospital in Eksjö, Jönköping County, Sweden. The unit includes an outpatient clinic, an inpatient ward with 15 beds, and an affiliated unit for endoscopic examinations[11]. The Highland health care system consists of eight health care centers for primary care, and the 280-bed Highland Hospital responsible for secondary and acute care, in all serving 110 000 inhabitants. The health care delivered is tax financed, and the county council functions both as insurer and provider of the care.

To date, no quality measures for IBD care have been generally approved. Feasible and practical quality measures were selected in order to evaluate the quality of care delivered within the local setting. The first act was to organize a registry with information, including patient addresses, diagnosis, disease duration, smoking habits, weight, and sex. Further information about the current prescribed medication and whether any surgical intervention had been performed was added to the files. Hemoglobin was chosen as the clinical marker to find anemia in the population, which may go undetected in many patients[25]. Further quality measures assessing the access to care[10] and quality of life (QoL) were chosen and integrated into the framework. Access was measured as the number of days from the referral being sent from the primary care physician until the patient received a scheduled consultation at the outpatient clinic, as well as the clinic's ability to offer an acute visit within two days after contact by a known patient. QoL was measured by using the short health scale (SHS)[26,27]. SHS is a questionnaire consisting of four questions about symptoms, function, worry and general health associated with the disease, reported on a 6-point graded likert scale. Patients were diagnosed according to clinical, endoscopic, and microscopic findings, and were sub-typed as having UC or CD. A senior gastroenterologist confirmed the diagnosis and registration of each patient. The status of the disease, i.e., subjectively experienced activity, was reported by the patients on the day of the annual check-up. Tumor surveillance colonoscopy was offered and performed according to guidelines for more than 95% of relevant patients. At the end of 2008, 481 patients were included in the local registry.

During the year, all patients were offered an annual check-up, which was preceded by a letter including a quality of life questionnaire and instructions for laboratory testing (hemoglobin) that could be performed at any of the primary care centers. An important part of the annual check-up was to remind the patient to contact the nurse by telephone with any questions or worries raised during the remainder of the year. Reinforcing this opportunity for telephone access was aimed toward avoiding misdirected care for IBD to other care settings such as the Emergency Department. In the redesigned clinical model, there was also a guarantee that access to an unscheduled visit for acute symptoms would be available within two days at all times. Data was collected by the specialist nurse or gastroenterologist at the time of the check-up, and computed every quarter but presented once a year.

In Table 1 an overview of the definitions, quality dimensions and components, purposes behind the measures, operational definitions, and data sources of the quality measures are integrated into the two quality models together creating the framework.

Ethical considerations

The ethical committee at the University of Linköping, Sweden, approved this study.

RESULTS

The first main finding is the presentation regarding how locally-selected clinical quality measures, integrated into two complementary models to create a framework, could be instrumental in assessing the quality of care delivered to patients with IBD. Further, the second main finding is the results presented in Table 2 for the local IBD population using the framework. The data describe the epidemiology of a patient population in the local care setting for IBD. To be stressed is the fact that more than 95% of the patients with IBD in the area are cared for by our care unit. The incidence of IBD was slightly below the expected level according to Swedish data[7]. This is probably explained by the older age distribution in the studied rural area. The prevalence of anemia is less than previously reported. Medication is presented for Crohn's disease and ulcerative colitis. Immunosuppressive medication, cortisone and anti-TNF-alpha are prescribed more for Crohn's disease compared to ulcerative colitis. Further, 5-aminosalicylic acid is prescribed more for ulcerative colitis compared to Crohn's disease. Table 2 show good access to care. Few surgical interventions were performed over the year. Three patients with ulcerative colitis underwent colectomy and three patients with Crohn's disease underwent incisions due to fistulas or strictures. No tumor was found in the population. Data was not processed statistically for differences between groups.

In the years before 2008, an average of 75% of the registered patients had a complete annual check-up documented, i.e., a telephone call or a visit in combination with QoL and/or laboratory tests. In 2008, patients without

Table 1 Overview of the quality framework presenting definitions, purposes, data sources and operational definitions for the adopted quality measures as well as properties of the applied models

	Characteristics of measures included in the framework					Properties of the models included in the framework	
	Quality measure	Definition of measure	Data source and data collection	Operational definition of measure	Purposes for the measure adapted from Behn	Quality dimension according to the clinical value compass	Quality components as part of the quality model of Donabedian
Patient data	Diagnosis	Inflammatory bowel disease	Local gastro registry	Crohn's disease and ulcerative colitis	Control, evaluation	Clinical dimension	Outcome
	Gender	Sex	Local gastro registry	female:male	Control, learning	Clinical dimension	Structure
	Age		Local gastro registry	Age [mean (SD)] range	Control, learning	Clinical dimension	Structure
	Disease duration	Début year	Local gastro registry	Years since time of diagnosis [mean (SD)] range	Control, evaluation	Clinical dimension	Outcome
Laboratory measures	Hemoglobin	Blood sample enabling detection of anemia associated with chronic disease, blood loss, or iron deficiency	Local gastro registry Tests were performed at the nearest primary care center and reported electronically	Cut-off points were defined as: mean (SD) normal ⩾ 120 g/L, anemia 100-119 g/L severe anemia < 100 g/L missing	Control, evaluation	Clinical dimension	Outcome
Medication	Prescribed medicine	Currently prescribed preventive medication	Local gastro registry	Prescribed medication: 5-ASA cortisone immunosuppressive anti-TNF-α no medication	Control, evaluation	Clinical dimension	Process
Surgical interventions	Incidence of surgery	Surgical interventions associated with IBD	ERS, searched for ICD codes for surgical interventions and IBD once a year	Type and numbers of surgical interventions: colectomy hemicolectomy loop ileostomy perianal/ fistula/ stricture incision revision abdominal scar	Evaluation	Clinical and cost dimension	Process
	Tumor incidence	Incidence of gastrointestinal tumors associated with IBD	Data from the national tumor registry retrieved once a year	Number and type of intestinal tumors associated with IBD according to diagnosis in records as ICD code	Evaluation	Clinical and cost dimension	Outcome
Quality of life	The Short Health Scale, SHS	SHS is a health related quality of life questionnaire consisting of four questions graded on a 6 point Likert scale.	Local gastro registry	Percent scoring 1 to 3 representing that the goal of the care was reached symptoms functioning worry wellbeing	Evaluation	Functional dimension	Outcome
Access to care	Waiting time	Referral from primary to secondary care	Local administrative data base	Number of days from the referral being sent from the primary care physician until the patient received a scheduled consultation at the outpatient clinic	Motivation, budget, learning, evaluation, promotion	A proxy for the satisfaction dimension	Process and outcome
	Waiting time for known patients	An acute visit is used for an urgent need of assessment due to deteriorating disease	Local administrative data base	The clinic's ability to offer an acute visit within two days after contact for known IBD patients	Motivation, budget, learning, evaluation, promote	A proxy for the satisfaction dimension	Process
	Contact route (before being admitted to hospital)	The place for the decision to admit the patient for inpatient care, i.e. either at the ER or the outpatient clinic	ERS Contact route was decided after finding indicators such as: where the note was written, if the note was written by an on call colleague or a gastroenterologist	The ERS was searched to find out where the decision was either at the ER or from the outpatient clinic	Learning	Cost and a proxy for the satisfaction dimension	Process

Hospitalization	Hospitalization	Individual and total numbers of admittances for IBD patients	ERS was searched for ICD codes and national data was retrieved from the National Board of Health and Welfare	ERS documented ICD code for IBD and hospitalisation	Motivation, budget, evaluation	Cost dimension	Process and outcome

IBD: Inflammatory bowel disease; ICD: International classification of diseases; ERS: Electronic record system.

Table 2 Quality framework applied to the inflammatory bowel disease care setting at the Department of Internal Medicine in Highland Hospital, Eksjö, Jönköping County, Sweden

	Quality measures from 2008	Crohn's disease	Ulcerative colitis
Patient data	Diagnosis	194	261
	Gender		
	Female:male	44%:56%	42%:58%
	Age (yr)		
	Mean (SD)	53 (± 15)	51 (± 15)
	Range	18-90	20-91
	Disease duration		
	Years since time of diagnosis		
	Mean (SD)	20 (± 13)	14 (± 10))
	Range	0-58	0-53
Laboratory measures	Hemoglobin		
	Mean (SD)	140 (± 12)	143 (± 13)
	Normal ⩾ 120 g/L	95%	96%
	Anemia 100-119 g/L	4%	4%
	Severe anemia < 100 g/L	< 1%	0
	Missing	16%	17%
Medication	Prescribed medicine		
	5-ASA	43%	56%
	Cortisone	16%	4%
	Immunosuppressant	34%	12%
	Anti-TNF-α	8%	2%
	No medication	31%	40%
Surgical interventions	Incidence of surgery		
	Type and numbers of surgical interventions:		
	Colonectomy		3
	Hemicolectomy	1	1
	Loop ileostomy		1
	Perianal/fistula/stricture incision	3	1
	Revision abdominal scar	1	
	Tumor incidence		
	Number and type of intestinal tumors associated with IBD according to diagnosis in records as ICD code	0	0
Quality of life	The Short Health Scale, SHS		
	Percent scoring 1 to 3 representing that the goal of the care was reached		
	symptoms	95%	98%
	functioning	88%	95%
	worry	91%	94%
	wellbeing	97%	96%
Access to care	Waiting time		
	Number of days from the referral being sent from the primary care physician until the patient received a scheduled consultation at the outpatient clinic	< 3 wk	< 3 wk
	Waiting time for known patients		
	The clinic's ability to offer an acute visit within two days after contact for known IBD patients	< 2 d	< 2 d
	Contact route (before being admitted to hospital)		
	The ERS was searched to find out where the decision was either at the ER or from the outpatient clinic	50%/50%	50%/50%
Hospitalization	Hospitalization		
	ERS documented ICD code for IBD and hospitalisation	29	17

Data from the annual check-up 2008. IBD: Inflammatory bowel disease; ICD: International classification of diseases; 5-ASA: 5-aminosalicylic acid; ERS: Electronic record system; SHS: Short health scale.

complete annual check-ups were offered a new visit or telephone call at the end of the year. Using this approach,

98% (471/481) of the IBD population had a documented annual check-up during 2008. Of nine patients not receiving a check-up, four refrained from participating in the study and five were missing. One patient (with CD) was excluded from the study because of particularly severe disease demanding various levels of hospitalization on a more or less continuous basis.

DISCUSSION

Quality improvement (QI) forms a link between the study of disease (science) and clinical care (management)[28] and provides better management of the planning, delivery, and assessment of care. The need for a general assessment tool for IBD care has been emphasized several times over a number of years[3,5]. This study is, to the best of our knowledge, one of the first to present how two generally acknowledged quality models[12,13] with integrated clinical quality measures can be applied as a quality framework and tested in clinical practice at a single center in an IBD population. The intent was to evaluate the quality of care delivered to a population of patients with IBD in the Highland health care area, Jönköping County, Sweden. Because there are few other frameworks currently available, there are problems with comparing results and usage, which needs to be done when future research is available.

The framework offers a map of the epidemiology of all patients affected by IBD in a local setting. This is a prerequisite and a foundation for any further analysis and improvement effort. Interesting results were found in the population as presented in the framework. Anemia is a well-known complication of IBD, caused by a combination of bone marrow suppression secondary to chronic inflammation and blood loss from intestinal bleeding. The reported prevalence of anemia from different IBD care settings and patient populations ranges from 9% to 74%[29]. In this study, anemia was detected in 4% of UC patients and 5% of CD patients, as shown in Table 1. Less than 1% had severe anemia. However, the mean hemoglobin for all study groups was comparable to that of a healthy control population. The detected prevalence of anemia has even improved compared to previous findings in the same population[10]. The clinic has used the findings of incipient anemia to offer extra visits to the outpatient clinic, and/or more thorough laboratory investigations to identify the reasons behind these findings. The analysis of hemoglobin is inexpensive, valid, and simple to perform. Treatment of anemia on an individual level is well established. Altogether, it is a feasible and useful finding to apply as a quality measure within a population.

Knowledge of how well guidelines for medication are implemented in an IBD patient population is sparse. The prescription pattern presented is in line with reports from centers in Norway[30,31] and Canada[32]. It provides an example of how quality measures can be directly related to guidelines and thus provides important information about the quality of care delivered[33]. The incidence and type of surgery is presented in Table 1. Surgical intervention rates were low in our study, and should be interpreted cautiously. The figures of access and number of hospital admittances for IBD could be used in future work as a benchmark for other clinics and as comparisons to national trends in Sweden or in America[34,35].

The future use of the framework is associated with the way in which data retrieval could be improved. This could be done in several ways. One way would be to retrieve the data directly from the electronic medical record (EMR), and a second way would be to provide opportunities for the patient to deliver self-reported outcome measures directly into the EMR. In order to achieve this for additional quality measures, several steps are required. First, the suggested framework and measures need to be tested, discussed, and refined in a broader setting. Secondly, the measures need to be presented and followed as "real time" data on both an individual and a group/subgroup level in order to allow benchmarking. Thirdly, it should be possible to correlate quality measures with prescriptions, days off from work, and further changes in medication and/or treatment. An example of a "feed-forward" quality register[36] is already in place for patients with rheumatoid arthritis within the Swedish Rheumatoid Arthritis Registry (SRAR)[37,38]. In the SRAR register, it is possible to track individual patients as well as patient populations both locally and nationally and use this information to, for example, correlate their clinical status with the timing of newly prescribed biological drugs and days off from work[39]. The SRAR is regarded as one of the best quality registries in Sweden, and can serve as a model for future IBD registry work.

This study presents how locally-selected clinical quality measures, integrated into two complementary models to develop a framework, could be instrumental in assessing the quality of care delivered to patients with IBD. The selected quality measures noted less anemia in the population than previously reported, provided information about hospitalization rates and the few surgical procedures reported, and noted good access to the clinic. We believe that this approach of organizing and regularly utilizing data within our system is sustainable, and will enable future improvement in the quality and value of care for our IBD patients. We propose that the suggested framework and quality measures should be further tested, evaluated, and refined within the gastroenterological community.

COMMENTS

Background

In modern healthcare, there is often a gap between the expected level of healthcare delivery and the actual healthcare provided. This is also true for the care of inflammatory bowel disease (IBD) as highlighted by the American Gastroenterology Association. These stakeholders have called for action and challenged the gastroenterology community to find systems for quality assessment and improvement in IBD.

Research frontiers

Since the publication "Crossing the Quality Chasm" by the Institute of Medicine in America on the brink of the new millennium, the urge to improve quality of care

has been one of the main focuses in health care research. Unfortunately, few publications connecting this area to IBD have been published since that time.

Innovations and breakthroughs

The main outcome was the presentation of how locally-selected clinical quality measures, integrated into two complementary models to develop a framework, could be instrumental in assessing the quality of care delivered to patients with IBD. The selected quality measures of the framework noted less anemia in the population than previously reported, provided information about hospitalization rates and the few surgical procedures reported, and also noted good access to the clinic.

Applications

The framework offers a map of the epidemiology of all patients affected by IBD in a local setting. This is a prerequisite and a foundation for any further analysis and improvement effort.

Peer review

In this study, the authors created and applied a framework for quality assessment and improvement in IBD. They showed that the locally selected clinical quality measures, integrated into two complementary models to create a framework, could be instrumental in assessing the quality of care delivered to patients with IBD.

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