

Review

Quality of health care in inflammatory bowel disease and its assessment

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SUMMARY

Patients with inflammatory bowel disease (IBD) are consistently high users of health care services. They need continuous medication, frequent follow up visits, while their life expectancy is normal. One major parameter, which creeps into the assessment of quality of care, is organization of health care system. However, relatively little research exists on the characteristics and the organization of an ideal health care system which will effectively satisfy the needs of the chronically ill patient. Regarding money spent on chronic illnesses in terms of societal costs, IBD is less costly than, for example, coronary diseases, since loss of work hours, disability, or early death are less common. In terms of pure economic costs, IBD patients can be more costly than other chronic patients depending on age of disease onset and severity of illness. Crohn's disease patients consider cost aspects as an important element of quality more than ulcerative colitis patients do. Standard framework for the assessment of quality of care remains Donabedian's approach according to the *Structure-Process-Outcome* characterization. Lack of information is associated with more disease related worries and concerns of patients and, accordingly, with decreased quality of life. Finally, the patient's perception about high quality health care and his/her satisfaction as a "consumer" of health care services are extremely important issues for assessing quality of health care.

Key words: Inflammatory bowel disease, Ulcerative colitis, Crohn's disease, care, quality of care, health services, health system, patient's satisfaction

1. INTRODUCTION

Inflammatory Bowel Diseases [Ulcerative Colitis (UC), Crohn's Disease (CD)] are chronic diseases of the alimentary tract that can commence at any time during life but their highest incidence occurs between 15 and 35 years of age. They have a great impact during a very active period of life that often includes acquiring an education, developing a career and raising a family.¹ The prevalence of Inflammatory Bowel Disease (IBD) in Europe is 160-320 patients per 100.000 people and the incidence is around 16 new cases per 100.000 of population.^{2,3} Physical history of IBD is characterized by remissions and relapses. Disease characteristics are abdominal pain, diarrhea, rectal bleeding, weight loss, fatigue and fever. Extra-intestinal complications involving eyes, joints, skin and hepatobiliary system are also associated with UC and CD. Most of patients need continuous medication (maintenance medication) and are at increased risk of undergoing abdominal surgery and developing intestinal cancer. Current therapy is not curative but palliative, mainly supportive or immunosuppressive. Additionally, IBD patients have a normal life expectancy, so they are consistently high users of health care.⁴ The purpose of this review is to present and analyse several variables which influence quality of health care concentrated on IBD patients.

2. QUALITY OF HEALTH CARE

Quality of health care is not a new concept and there is an increased interest in its assurance and improvement.⁵

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There are many organizations in USA and Europe dealing with this concept⁶ (Table 1). Experts have struggled for many years to devise a concise, meaningful and generally applicable definition for quality of health care. In 1980, Donabedian defined care of high quality as “that kind of care which is expected to maximize an inclusive measure of patient welfare, after one has taken account of the balance of expected gains and losses that attend the process of care in all its parts”.⁷ In 1984 the American Medical Association defined high-quality care as care “which consistently contributes to the improvement or maintenance of quality and/or duration of life”.⁸ One of the most widely accepted definitions, formulated in 1990 by the Institute of Medicine, holds that quality consists of the “degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge”.^{9,10} It is obvious that several definitions of care of high quality are both possible and legitimate, depending on our location in the health care providing system and on the extent and nature of our responsibilities.¹¹⁻¹³

3. HEALTH CARE USE IN IBD

Chronically ill patients, such as IBD patients, are “high” users of health care services.⁴ Additionally, a sometimes early onset of disease and frequent relapses intensify the need for health care services. Quite often relapses lead to hospitalization, whereas, in remission, outpatient visits are needed for follow-up, endoscopic surveillance and monitoring of medication.¹⁴ Although IBD patients seek health services fairly frequently, they seem to know very precisely the kind of health care they are looking for. Their physician should be easy to reach

Table 1. Organizations dealing with quality of care assurance and improvement.

Organization
- Joint Commission on Accreditation of Health Care Organizations (JCAHO)
- National Committee for Quality Assurance (NCQA)
- The American Medical Accreditation Program (AMAP)
- The American Accreditation Health Care Commission/Utilization Review Accreditation Commission (AAHC/URAC)
- Accreditation Association for Ambulatory Healthcare (AAAHC)
- Foundation for Accountability (FACCT)
- Health Care Financing Organization (HCFO)
- Agency for Healthcare Research and Quality (AHRQ)

and they usually want to be seen by the same gastroenterologist, a continuity in their treatment.¹⁵ Issues concerning organization of health care services’ are fundamental components of quality of care. Generally known predisposing factors, such as age, sex, education and marital status, do not seem to influence health care utilization in IBD.^{16,17}

In IBD patients no study has been conducted so far to assess the total concept of quality of care. A recently published study has presented an instrument that assesses the opinion of IBD patients on the quality of provided health care.¹⁸ This study, where two University Gastroenterology centres from Greece – Ioannina and Heraklion – took part, showed no difference between UC and CD patients when evaluating patients’ opinions regarding quality of provided care.

4. HEALTH CARE SYSTEM AND COSTS

A health care system is substantially a complex network of relationships among patients-“consumers”, health care providing organizations and health “politicians” who are responsible for financing and determining the goals of health policy. Although a national health care system is a crucial issue in quality of care, little research exists on the ideal organization of a health care system and on how this system can effectively satisfy the needs of chronic patients. Large prospective studies are needed in order to identify, develop and implement a system of care which will be able to respond to the specific problems of chronically ill patients.^{19,20}

Most money provided for health care is spent on chronically ill patients and their associated complications. In terms of “sociatal cost” (lost working hours, early retirement, early death) IBD is less costly than other chronic diseases such as rheumatic and coronary diseases, since disability or early death are less common in IBD and disease prevalence is lower.^{21,22} However, in terms of economic costs, IBD can be more costly, depending on the age of first diagnosis and physical history of the disease (frequency of exacerbations, extraintestinal manifestations, hospitalizations, surgical operations).^{21,22} As life expectancy increases, the prevalence of chronic diseases will rise, resulting in an increased demand for health care services and therefore for increased funds for health.²³ Patients with CD consider cost aspects an important element of quality of care, more than UC patients do.²⁴ This could be due to the more complex physical history of the disease and to more expensive medication (e.g. anti-TNF α) for CD patients.

5. ASSESSING QUALITY OF HEALTH CARE

5.1. The Structure-Process-Outcome Approach

According to Donabedian, a leading figure in the theory and management of quality of care, quality of health care can be assessed on the basis of structure, process or outcome.¹¹

Structure refers to characteristics of the organization where care is provided. This includes material resources (facilities, equipment, money), human resources (number and qualifications of personnel) and organizational structure (such as medical staff organization, methods of follow-up, methods of reimbursement).^{11,25}

Process data are components of the encounter between physician and patient. They denote what is actually done in giving and receiving care. They include patient's activities in seeking care and doctor's activities in making a diagnosis and suggesting an applicable treatment. Process also includes the "human" characteristics of the physician (politeness, interest in the patient), as well as issues of patient's information and his/her ability to participate in decision making about medication and treatment.^{11,25-27}

Outcome data refer to the effects of provided care on a patient's or a population's health status. Improvements in a patient's knowledge and behavior are included in this definition.^{11,25}

5.2. Information

A special aspect in assessing quality of health care is the amount of information the patient is given. It has been reported that IBD patients reported lack of adequate information as one of the most significant problems regarding their care.²⁸⁻³⁰ Insufficient information has been associated with higher levels of anxiety and disease related worries and therefore with lower quality of life.³¹ Patients mostly look for information about i) aspects regarding the nature of the disease like etiology, increased risk of malignancy, infectious matters, and heredity, ii) aspects regarding the impact of the disease on their social and professional life and, iii) aspects referring to their treatment and its possible side-effects.³² (Table 2)

5.3. Patient's Perception

Many physicians and health care professionals believe that their opinion about quality of provided care is identical to that of the patient. However, this belief has never been confirmed. A patients' opinion about quality of care is usually completely different from that of health care professionals, as shown in many studies.^{15,33-37} In early

studies of the patients' perception on quality of care, it was found that opinion of patients resulted in higher scores, indicating the need for evaluating both patients' and professionals' opinion in order to create a complete view of the care provided.³⁸ In a recent study van der Eijk et al have shown that perceptions of IBD patients and their treating physicians differed significantly. Physicians consider accessibility to care and information as important aspects, whereas patients appreciate competence of the treating physician, continuity of care and cost aspects more. Greek patients and physicians who participated in this study had similar scores as totals.³⁹

5.4. Patient Satisfaction

In 1990 the International Organization of Standardization gave the following definition regarding the quality of a product or a service provided: "The totality of features and characteristics of a product or service that bear on its ability to satisfy stated or implied needs".⁴⁰

Accordingly to this definition a patient's satisfaction may be considered as one of the desired outcomes of care, even an element of health status itself.^{11,41,42} All patients, but especially the chronically ill are considered experts in evaluating quality of health care services.^{27,43}

5.5 Quality of health care in IBD; the QUOTE-IBD questionnaire

Some selected aspects of quality of care have been studied in IBD patients, mostly the information issue²⁸⁻³⁰ but no study has been conducted to assess the total con-

Table 2. Information needs of IBD patients classified in themes

A. Disease nature	- infectious
	- heredity
	- etiology
B. Extraintestinal complications	
C. Side-effects of treatment	- medication
	- surgery
D. Examinations needed	- endoscopy
	- CT scan
	- enteroclysis
E. IBD and:	- nutrition
	- pregnancy
	- sexual life

cept of quality of care. A recently published study has presented an instrument, the QUOTE-IBD questionnaire, that assesses the opinion of IBD patients on provided quality of health care.¹⁸ This instrument evaluates the quality of provided health care, focusing on eight care dimensions: competence, courtesy, accessibility, information, continuity of care, accommodation, autonomy, and costs. No difference between UC and CD patients was found in any dimension when evaluating the patients' opinion regarding quality of provided care. Female patients gave poorer evaluations of provided care than male patients, especially for the competence, courtesy and information aspects.¹⁸

6. PERSPECTIVES

Interest about assurance and improvement of quality of care is now great worldwide. Chronically ill patients, like IBD patients, are "high" users of health care services, and therefore represent an important partner in the attempt to improve these services. The development of validated questionnaires for assessing quality of provided care is an important step towards improvement of health care services. Their usefulness in planning interventions to health policy and as an instrument for clinical trials, the validated questionnaires will be of paramount importance in means that future.

ACKNOWLEDGEMENT

AG Pallis is a recipient of an educational grant by JANSSEN CILAG

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