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TOPIC HIGHLIGHT

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Quality of care in Crohn's disease

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Abstract

Crohn's disease (CD) is a chronic and progressive inflammatory disease of the intestine. Overall, healthcare delivery for patients with CD is not optimal at the present time and therefore needs improvement. There are evidences which suggest that there is a variation in the care provided to patients with CD by the inflammatory bowel disease (IBD) experts and community care providers. The delivery of healthcare for patients with CD is often complex and requires coordination between gastroenterologists/IBD specialist, gastrointestinal surgeon, radiologists and IBD nurses. In order to improve the quality of health care for patients with CD, there is need that we focus on large-scale, system-wide changes including creation of IBD comprehensive care units, provision to provide continuous care, efforts to standardize care, and education of the community practitioners.

Key words: Inflammatory bowel disease; Quality assurance; Quality indicators; Outcome; Comprehensive care units; Quality improvement

Core tip: Crohn's disease (CD) is a progressive inflammatory disease of the intestine. Overall, healthcare delivery for patients with CD is not optimal at the present time and therefore needs improvement; Despite availability of national and international practice guidelines, there is a variation in the care provided to patients with CD; There is a need to develop well defined quality indicators which assures delivery of adequate care of the disease.

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INTRODUCTION

Crohn's disease (CD) is a chronic and progressive inflammatory disease of the intestine, which occurs because of interaction between, immunological factors, environmental factors and gut microbiome[1].

At the onset of the disease, the majority of patients with CD while have ulcerations in the intestine, the course of the disease gets complicated with patients developing strictures and fistula in the intestine[2]. In a study including 297 patients with CD over 25 years, Louis *et al*[3] reported a change in the behavior of the disease in 46% patients from non-stricturing, non-penetrating to either stricturing (27%) or penetrating (29%) disease in the first 10 years of follow-up. Because of the progressive nature of the disease, patients with CD are more likely to require not only repeated hospitalization but also surgical interventions[4,5].

While majority of patients with CD generally present in third and fourth decade of their lives, approximately one fifth of them become symptomatic during childhood and nearly 5% of them even before 10 years of their age[6]. Failure to thrive, retardation in the linear growth and defect in bone formation are the major issues in pediatric patients with active CD. Even puberty gets delayed in children patients with CD. Therefore, induction of re-

mission of the disease and maintenance of remission before the onset of the puberty is essential for children patients with CD. A good control of inflammatory activity is required to prevent or even minimize the consequences of a missed pubertal growth spurt and the maintenance of pre-pubertal levels of sex hormones. Since more than 90% of the bone mass is attained during childhood and adolescence, inflammatory diseases during this period can affect bone development and may ultimately lead to osteopenia and make them susceptible to fractures[7].

Till a few years back, control of symptoms has been considered to be an end point of treatment of CD; over the past years however, healing of mucosal ulcerations has emerged as a major therapeutic goal for patients with CD[8-10]. There are now evidences which suggest that healing of mucosal ulcerations with anti-inflammatory/immunomodulators or biologicals has a potential for changing the natural history of the disease and the available primitive evidences suggest that there is reduction in the rate of hospitalization and requirement for surgery in those patients who attains mucosal healing[11].

The treatment of CD depends upon the activity (active phase, remission phase), location, extent and behaviour (inflammatory, stricturing, fistulizing) of the disease[1]. The treatment needs to be tailored for each patient. The choice of treatment is also influenced by well-known negative prognostic predictors of CD such as young age of onset, presence of extensive disease, stricturing disease, and positive smoking history[12].

Chronic disease management has become a significant focus for providing a quality and continuous care of these diseases in order to decrease their morbidity and mortality[13]. Care of chronic diseases requires a continuous and optimal care including use of newly discovered with proven value diagnostic or therapeutic strategies. The question arises, are we providing a standard and quality care to patients having chronic diseases? In a landmark study from US, based on review of medical records and telephonic interviews, has shown that only 57% of patients attending the outpatients clinic regularly receive recommended standard of care for a variety of acute and chronic illnesses[14]. This study has raised an important concern and further highlights the importance of delivering an evidence based care and preventative measures to patients with chronic diseases in order to decrease complications, hospitalizations, and death.

QUALITY OF CARE IN INFLAMMATORY BOWEL DISEASE IS SUBOPTIMAL

Since there is no definite cure for most patients with CD, the main objectives of treatment therefore include induction of remission and maintenance of remission; minimization of complications of the disease such as strictures, fistulae, osteoporosis, short-and long-term toxicities of the drugs; improvement in quality of life; decrease in number of hospitalizations and surgeries; and maintenance of linear growth in pediatric patients. The practice of many chronic diseases is generally guided by evidence based literature and on the guidelines of both International and national societies[12,15-17]. While there is some degree of variability amongst the guidelines, the essential components remain more or less similar, since such recommendations are based on the available evidences derived from a body of published literature. Since CD is a disease with heterogeneous characteristics, treatment is generally tailored or individualized for a particular patient[12,15-18].

There is a variability in the treatment provided by an expert and a general practitioner especially for diseases, which are heterogeneous in their clinical behavior and where treatment options and guidelines are still emerging[19]. A variability in the care of a particular disease provided by various physicians is regarded as an index for poor quality of care. In inflammatory bowel disease (IBD), there is evidence of a high degree of variation of care for both patients with UC and CD[19]. In order to develop quality indicators for care, it is therefore, critical to understand the current status of care of such diseases. If current practice varies widely and is not well standardized, it calls for standardization of treatment protocols.

In a survey on the management of CD by IBD experts and community care providers, Esrailian *et al*[19] reported that there was good agreement in the decision making of diagnostic testing between community care providers and the IBD experts. In the management decisions, there was significant disagreement between community care providers and IBD experts[19]. While most community care providers in this study believed that 5-aminosalicylate products were appropriate across a variety of presentations of CD, IBD experts were significantly less likely to endorse 5-ASA use in patients with CD. In contrast to 5-ASA results, experts and community providers generally agreed with each other on the use of immunomodulators, infliximab and antibiotics in CD. Furthermore, the differences existed not only between community care providers and IBD experts; there was marked differences in the management decisions taken by various IBD experts, especially with the use of immunomodulators in newly diagnosed CD and perianal fistulizing CD[19].

Another study including patients with CD and UC also suggested that patients with IBD often do not receive optimal medical therapy. The main points include suboptimal dosing of 5-ASA and immunosuppressive therapy, prolonged use of corticosteroids, underuse of immunosuppressive drugs, non-compliance to use of calcium and vitamin D, and inadequate screening for colorectal cancer[20].

QUALITY IMPROVEMENT AND QUALITY ASSURANCE

Quality improvement (QI) and quality assurance (QA) are now becoming essential components of public services including delivery of healthcare services. While quality improvement is used to describe the process of

Table 1 Measures to provide quality care to patient with Crohn's disease

Delivery of high quality, safe and integrated clinical care for IBD patients based on multi-disciplinary team called IBD Comprehensive Care Unit
Delivery of care at the local center and if needed with rapid access to more specialized IBD care center
Patient education and support
Care for IBD patients that is patient-centered, responsive to individual needs
Regular audit of the care provided and outcomes

IBD: Inflammatory bowel disease.

implementing evidence-based interventions to bridge the disparities currently present in various healthcare systems; quality assurance is defined as planned, systematic activities that are implemented to ensure that a level of performance is attained[21]. In any chronic disease process the three main objective of care include improvement in population health, improvement in patient's experience of care, and at the mimimal cost; all three together are defined as Triple Aim of the disease[22].

The essential building blocks for quality improvement efforts are the proper identification and implementation of effective quality indicators. These quality indicators are measurable elements of practice performance for which there is evidence or consensus that they may be applied to assess and improve the quality provided[23-25]. The types of quality indicators have been broadly categorized as structural measures, process measures and outcome measures. Structural measures are indicators to do with the structure of the health system such as staffing, equipment, and electronic medical records. Process indicators are the processes of providing care such as investigations, treatment, and interactions with patients. Outcomes indicators assess the outcome of patients such as quality of life, patient satisfaction, prophylactic vaccines, mortality and morbidity. While improvement in all categories of indicators is desirable, process measures have garnered the majority of the attention, as they are most easily modifiable.

EFFORTS TO IMPROVE QUALITY OF CARE

Health care measures such as use of electronic medical record systems, automated entry of diagnostic and therapeutic orders, decision support tool at the point of care, and routine measurement of and reporting on quality have been shown to improve the quality of care[14]. In 2004, with funding from the American Board of Pediatrics, a group of care providers started a "research and improvement network", focused on improving care for children and teens with CD[26]. ImproveCareNow (ICN) network invited care providers to form collaboration to record information from all the patient visits and the care they were providing to children with IBD[27]. With insitution of protocal based recording of care, the group observed an increase in the proportion of visits with complete disease classification, measurement of thiopurine methyltransferase (TPMT) before initiation of thiopurines, and patients receiving an initial thiopurine dose appropriate to their TPMT status. Furthermore, an increase in the proportion of patients either CD or UC having inactive disease on follow up was observed, suggesting a better care. The number of patients taking prednisolone also decreased[28]. With the similar changes in the practice at IBD center at Cincinnati Children's Hospital Medical Center, there was an increase in the clinical remission rate from 59% to 76% ($P < 0.05$), decrease in frequency of steroid use from 17% to 10% and an increase in patients having Short Pediatric Crohn's Disease Activity Index < 15 from 60% to 77%[29].

These preliminary studies from ICN are testimony that a large-scale pediatric IBD quality improvement network can change practice and improve the quality of care. The key measures required for the delivery of quality care to patients with CD is summarized in Table 1.

QUALITY INDICATORS FOR IBD

There is a lack of definitive guidelines on the measurement of quality indices in IBD. The American Gastroenterology Association has recommended 10 indices as a measurement of quality of care in IBD[30] (Table 2). Similarly, the Crohn's and Colitis Foundation of America have also proposed a questionnaire for the assessment of quality of care of patients with IBD[31,32] (Table 2).

In order to identify a set of quality indices, Calvet *et al*[33] conducted a two-round web-based survey including an expert panel of patient representatives ($n = 4$), nurses ($n = 7$), surgeons ($n = 2$) and physicians ($n = 18$) using Delphi consensus-based approach. The expert panel selected a core set of 56 QIs (including 12 structure, 20 process and 24 outcome related). Structure and process quality indicators highlighted the need for multidisciplinary management and continuity of care. The key outcome quality indices focused on the adequate prophylaxis of disease complication and drug adverse events, the need to monitor appropriateness of treatment and the need to reinforce patient autonomy by providing adequate information and facilitating the patients' participation in their own care. The panel also suggested that there should be an IBD team and the team should be consisted of gastroenterologists, radiologists, surgeons, endoscopists, IBD nurse, and stoma management specialists.

HOW TO IMPROVE QUALITY OF CARE: A CONCEPT OF IBD COMPREHENSIVE CARE UNIT

The care of CD requires a coordinated action of a number of health care professionals such as a gastroenterologists/IBD expert, gastrointestinal surgeon, radiologist, stoma care personel and well trained nurses. All of them can

Table 2 Quality of care indicators in inflammatory bowel disease

	Quality of care indicators
10 quality of care indicators by American Gastroenterology Association	IBD: type, anatomic location and activity all assessed IBD preventive care: corticosteroid sparing therapy IBD preventive care: corticosteroid related iatrogenic injury - bone loss assessment IBD preventive care: influenza immunization IBD preventive care: pneumococcal immunization Testing for latent tuberculosis before initiating anti-TNF therapy Assessment of hepatitis B virus before initiating anti-TNF therapy Testing for Clostridium difficile - inpatient measure Prophylaxis for venous thromboembolism - inpatient measure IBD preventive care: tobacco user - screening and cessation intervention
CCFA top 10 quality outcome indicators of IBD	Corticosteroid use Proportion of patients with steroid-free clinical remission for a 12-mo period Proportion of patients currently taking prednisone Number of days per month and year lost from school or work because of IBD Number of days hospitalized per year because of IBD Number of emergency room visits per year for IBD Proportion of patients with malnutrition Proportion of patients with anemia Proportion of patients with normal disease-targeted health-related quality of life Proportion of patients currently taking narcotic analgesics Proportion of patients with nighttime bowel movements or leakage Proportion of patients with incontinence in the past month

IBD: Inflammatory bowel disease; TNF: Tumor necrosis factor; TB: Tuberculosis.

form a IBD Comprehensive Care Unit (ICCU). While it is commonly accepted that ICCUs facilitate the provision of quality care to patients with IBD, a structure of ICCU is still not well defined[33].

The cost of implementing some of these quality measures is modest suggesting that substantial improvement is possible. Individuals at all levels from senior clinicians to administrative staff should be encouraged to identify areas of potential improvement in the quality of care. In all settings, quality indicators should be seen as a team effort of the practice as a whole. One of the important features of chronic disease care is to provide continuous care, such as from clinic to home, interval reminder and also in between appointment care.

ANTAGONISTIC VIEW

While most supports the view that providing a quality care is a essential element of healthcare delivery system, a few believes that the imposition of quality measures may disrupt the art of medicine and the precious minutes at an office visit may be lost in documentation rather than spending time in thoughtfully delivered health care[22,34].

PROVIDING QUALITY OF CARE IN RESOURCE LIMITED COUNTRIES

Providing quality care in resource limited countries is a real challenge. The barrier to impart quality of CD care in resource limited countries may mainly be structure related such lack of optimal number of IBD experts, lack of diagnostic facilities, and affordability and non-referral of patients to tertiary care centers.

CONCLUSION

The delivery of healthcare for patients with CD is often complex and requires coordination between gastroenterologists/IBD specialist, gastrointestinal surgeon, radiologists and IBD nurses. Overall, healthcare delivery for patients with CD may not be the optimal at the present time and therefore needs improvement. There are evidences which suggests that there is a variation in the care provided by the IBD expert and general practitioner. To make substantial improvements in the quality of health care available to all patients, there is need of making large-scale, system-wide changes.

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