

Can Inflammatory Bowel Disease Unit Really Improve the Quality of Care?

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Abstract

Background: IBD represent rising pathologies with increase in incidence and prevalence, especially in more industrialized countries.

Methods: It needs to study an organisational model, made up of several professional positions collaborating each other. IBD-Unit's purpose is, firstly, improve the quality of care and, secondly, decrease the expenses. In fact, chronic pathologies take the majority of national healthcare systems resources, therefore the decrease of costs is primary.

Results: Planning and creation of an IBD-Unit provide for two central position, gastroenterologist and IBD-nurse, to coordinate relationships and specialized evaluations that, we believe, should be conducted together with other specialists. This should quicken clinic decisions and make more appropriate therapeutic decisions.

Conclusions: IBD represent a model of multidisciplinary pathology that need a shared approach from the beginning.

Keywords: *Inflammatory Bowel Disease; Multidisciplinary Team; IBD Nurse; Management*

Introduction

Inflammatory bowel disease (IBD) is associated with impaired health-related quality of life (HRQOL) and adherence; are diffuse worldwide with a prevalence of about 2% in North America and some European countries, and are rapidly increasing in China and Australia. IBD have a high rate of complications (about 20%) such as infections, kidney gallstones, osteoporosis, abscesses and fistulas that often require surgical intervention.

Patients with IBD have lower life expectancy, worse quality of life, and reduced work productivity when compared with health population. Moreover, they have increased risk of developing tumors, high rate of hospital admissions, and longer hospital stay than all other gastroenterology diseases but liver cirrhosis [1].

General practitioners working in western National Health Services often deal with many chronic diseases, but 70% of them do not take care of IBD, because of either the complexity of these pathologies with frequent multi-organ involvement, or the lack of tools supporting them in the management of the patients.

To date, endoscopic remission (in particular for ulcerative colitis), improvement of quality of life, reduction of surgical interventions, and reduction of long-term cost of care are the main goals of the treatment of IBD. Therefore, the patients with IBD need a comprehensive approach aimed at satisfying their expectation of well-being and favouring their compliance to the treatment as well as to the disease itself [2].

Methods

Objectives of the IBD Unit

The IBD unit involves a multidisciplinary team aimed at shortening the time to the diagnosis, facilitating the care giving, and improving both the quality of life and clinical outcome. The multidisciplinary approach is necessary because of the multi-organ involvement of IBD that requires the expertise of different specialists. For instance, the perianal disease needs the contribution of radiologists, surgeons, and gastroenterologists, and when abscesses occur the drainage, seton placement, control of their correct placement, and therapy with TNF are sequential and complementary treatments linked to each other [3,4].

The IBD Unit involves several specialists who deal with the medical, biological, psychological, and organizational issues of the disease, planning the most suitable approach of care.

The core team of the IBD unit should be permanent and constituted by a gastroenterologist, a surgeon, a radiologist, a pathologist, a pharmacist, and a nurse experienced in IBD. The team goes beyond the idea of patient as an “object” that has to be cured, planning the most suitable approach of care (multidisciplinary evaluation). The team promotes individual duty to encourage adequate life-styles to maintain singular and common health; it guarantees the monitoring of supplied services quality and starts shared paths with social-health territorial net [5].

Core team IBD

The core team of IBD is constituted by a main and steady unit that should accurately organize meeting with patients, with other specialists, and instructive and scientific meetings to improve every team member [13].

Main unit should consist of a gastroenterologist, that coordinates and manages the activity of team, together with another main position for efficiency, the IBD-specialist nurse. There should also be: a surgeon, for abdominal surgery in IBD, in every way IBD show up; a radiologist, to understand clinical requests and reinterpret radiological images linking to the specific clinical case; a pathologist, to diagnose made biopsies precisely; a pharmacist, a rising position, responsible for the use of expensive and hospital exclusive drugs [7].

We could also define the members of an accessory team, essential when asked: the dietician, that defines behaviour therapy, is critical with young patients; the psychologist, debated role in literature, should reduce flare-ups. However, psychological and psychotherapeutic training remains essential to turn on new coping mechanisms. Caseworker seems to get greater relevance about the management of familiar background. Furthermore, a dedicated paediatrician should be present, to deal with transition to adolescence, in addition to the treatment of paediatric patients [6,9,11].

In account of immunologic disease IBD-linked incidence and high rate of extraintestinal involvements, it needs to provide for a dedicated rheumatologist; to completion, by demand as accessory but resolved, there should be a dermatologist, an oculist and an infectious disease specialist (the latter has been considered in team after the application of immunosuppressive drugs).

Scientific team meetings - about biological therapies, management of polyps in IBD and dysplasia, psycho-social management of patients, etc... are essential to enhance IBD-team quality and efficiency, updating single members. Team meetings are also necessary to manage the approach of care for complex patients, that require specialized expertise, since gastroenterologist does not deal with necessary expertise to solve extraintestinal involvements [8].

The professional role that underlines an eminent team is the surgeon, that should have a specific interest and appropriate experience [12]. The interaction between surgeon and gastroenterologist has to be defined inside a clear organization and go beyond individual opinion. Surgical direction has to be collective and shared between gastroenterologist, surgeon and patient [14,15].

It is important that reconstructive surgery, as ileo-anal pouch, is performed in a reference centre, to manage potential complications with a specialized surgeon [16].

A fundamental targets of multidisciplinary team is to ensure the access to urgent gastroenterological visit; there should also be accesses and dedicated spaces to specialist visits.

In a specialist surgical visit setting has to be a room, for example, for stoma management. A devoted endoscopic room for IBD patients should have appropriate tools to follow-up (for example magnification chromo-colonoscopy). Concerning radiology should be considered reserved visit for ultrasound, CT, MR [18].

Another aim is to define quality markers to evaluate diagnosis and follow-up, treatment efficacy, hospital unit features, enrolment process, continuous training.

As said previously, the interaction between team members has to be well defined. Team activity has to result in adherence to guidelines: for example, standardise and documented reports, recorded diagnosis at first visit, therapeutic algorithm including since primary care to specialized visit, parameters to choose hospitalisation and, possibly, surgery [14].

To consumers, team has to provide didactic material to healthcare education, to follow-up management; furthermore, it is necessary encourage patients' forum and patient open days.

Patients are motivated to read up informations, achieved from recognized IBD organizations.

Within the team, an overlooked role is patients' association's delegated, that should have a central position to mediate treatment, compliance with treatment, dates and follow-up [10].

Furthermore, the same patient belongs to team; therefore, shared meetings have to be congruent to patient requests.

If there are not suitable quality of care and shared management, a single centre competences should also be advanced, but that centre is few useful. There are several experts able to manage various IBD manifestations, but few definitive if not a member of a multidisciplinary team.

NICE guidelines specify, for certain, need for multidisciplinary approach to IBD: "discuss the disease and associated symptoms, treatment options and monitoring: with the person with ulcerative colitis, and their family members or careers as appropriate and within the multidisciplinary team (the composition of which should be appropriate for the age of the person) at every opportunity" [24].

Apply the principles in Patient experience in adult NHS services (NICE clinical guideline 138).

IBD nurse: Complex approach to outpatient visit

IBD nurses "appeared" in UK hospital to find a solution for several patient problems: access to the gastroenterology team during periods of exacerbation was poor and that prolonged periods of ill health had an impact on patients' home lives, sexual relationships and work life.

The level of understanding that patients with IBD had about their condition and its management was poor, infact a considerable number of patients were unable to describe the pathology of their condition and the rationale of their therapeutic management patients are educated around coping mechanisms, pregnancy, lifestyle choices, holiday and travel, smoking cessation, nutritional status, compliance with medication, colorectal cancer and osteoporosis awareness.

Long-lasting waiting times, provided data - sometimes scarce - and patient need for answers to specific questions and psychological support make basic nurse figure that has to develop a care plan for complex patients [19].

Didactic and informative role has to share and clarify the effect of IBD in daily life, support to management a disease that should remain invisible in social setting, hide symptoms and signs.

Between various tasks of IBD nurse is to encourage access to services, reorganize specialized outpatient activity, organize listening and reception points with qualified staff (filter action), collaborate with psychologist for individual meeting, or promote support group.

IBD nurse has a head role to inform the patient, support expressing doubts to adjust prejudices, identify personal and social resources, guarantee entourage to diagnostic, healthcare path and monitor motivational aspects [20].

Traditional outpatient clinic roles are: review of patient's medication, symptoms, blood tests, endoscopies, radiology reports to provide diagnosis and follow-up (expert advice and information; monitoring of drug related AE; in cases of disease worsening or therapy resistance)

- Further diagnostic investigations
- Specific therapies
- Regular appointments.

However, episodes of remission and flare-up are not predictable so a flexible organization is needed when dealing with patients suffering from IBD.

A more tailored care is:

- Feasible
- Effective
- Safe
- Cheaper.

Nurses in the IBD outpatient clinic offer more than merely picking up tasks which have been discarded by the medical profession:

- Behaviors, skills and personal attributes displayed by IBD specialist nurses make a real difference to patient care.
 - Helpline provider: Information provider; Rapid access manager.
- Case manager
 - Inpatient discharge
 - Therapy manager
 - Paediatric transition care
- Educator
 - Counsellor
 - Smoking cessation support for CD patients
- Researcher

Promoting relationship with healthcare (improving compliance), allowing patients to rearrangement resources and react to disease, simplify rehabilitation, supporting patient to free himself from physician dependence, encouraging prevention and care capacity (patient empowerment), improving best condition for patients to take part in healthcare decisions, beyond informed consent, assuming a coresponsability in his own health management [21].

Costs management

When an over-structure is proposed, it needs to analyse what and how it offers and the organization. If it's true that exist a staff and technologies related price, there is also an organizational process related ideational price that can make just supportable the previous

costs. Crohn's disease and ulcerative colitis represent a worldwide social issue with elevated costs for society. The elevated healthcare standards involve very expensive but efficient therapies. The aims are remission maintenance and reduction of complications, improving the quality of life. All that previously seems an increase of expenditure, represents a huge and incalculable a reduction of indirect costs. The improvement of plan and efficiency, with optimization of resources application (diagnostic and therapeutic) implicates a minimal initial increase of costs, about human resources, but entails, as a result in the medium and long term, an improvement of quality of care with the same assistance devoted time [23]. Other studies are necessary to evidence the decrease of costs, real aim for health system. The goals are dehospitalization and outpatient management: these two goals decrease direct and indirect costs significantly [22]. The establishment of control mechanisms for participants is important to start a multidisciplinary project. Firstly, there is plan ideation, then a study for real feasibility, literature data evaluation, target identification and a preliminary study of resources usage. Audits should be considered to allow all processes for change and improvement. The multidisciplinary team has to share updating and verifying errors meetings

Conclusions

In addition to the clinical application of advances in treatment and monitoring, the availability of new therapies for the treatment of IBD has raised expectations of improved outcomes, i.e., achieving and sustaining deep remission. The establishment of standards for treatment and service delivery, together with aligning process will help to achieve these aspirations.

Inflammatory bowel diseases have become a rapidly expanding and dynamically changing challenge. Patients care improves with the IBD-unit planning, if patient is integral part. Actually, it needs a leader, that decides which professional figure is necessary every time, on the other and it is also essential the availability to be involved, also without an institutional role but giving own professionalism,

The responsibility for therapeutic decision remains personal but has to be shared between experts. In our IBD unit, the basic responsibility should be given to the gastroenterologist, that has several linking to deal with every disease manifestation [17]. A presented time to patient care should be determined, allowing meeting with every expert. Many different visits are not the solution, also if specialized, but it needs an evaluation in presence of the gastroenterologist and answer to specific questions (therapies - investigations - solutions). Therefore, IBD Unit is a clear but also invisible, based on interpersonal and not always definable relationships, structure. Quickening clinic decisions keep high-level quality of care and consequently decreasing costs for health system. Taking care of patient is not just an organizational model, but the expression of attention for singular patient (tailored), that is not the treatment of one apparatus but of a syndromic expression of one disease. IBD extraintestinal manifestations are not pathologies linked to one disease but epiphenomenons of that, although needing of several experts. This is also explicated in latest ECCO guidelines: "Up to 50% of patients with inflammatory bowel disease experience at least one extra-intestinal manifestation; the management of complex extra-intestinal manifestation should be discussed in a multidisciplinary team meeting".

Realizing aspirations by aligning standards in IBD clinics at an individual patient level key actions taken by healthcare professionals at diagnosis and monitoring continuing care can help to optimize their care. At an institutional level these aspirations can be met by aligning processes and standards of care. Inside the team, ask the colleagues, ask about problems and solutions (Proactive approach), ask about experience (Ideas and results),ask the patients (Patient centered care), that is to say discuss with (and learn from) colleagues, and talk to the consultant and negotiate with administrators, too!

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