Best Practices in IBD Care

Taking Steps to Introduce an Integrated Multidisciplinary Patient-Centric Care Model
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Executive Summary

Inflammatory Bowel Disease (IBD) has an enormous and underappreciated impact on individual Canadians, Canadian society, and the Canadian healthcare system. While our country has a sound base of IBD expertise and infrastructure, research suggests there are more effective models for best practice. The facts and recommendations in this report warrant our serious attention.

IBD overview

- Inflammatory bowel disease encompasses at least two separate disorders that cause inflammation (redness and swelling) and ulceration (sores) of the small and large intestines: ulcerative colitis (UC) and Crohn’s disease (CD).
- UC typically affects the innermost lining of the large intestine (colon) and rectum and occurs through continuous stretches of the digestive tract.
- CD can occur anywhere in the digestive tract. Diseased sections of bowel are often interspersed with healthy ones.
- Both UC and CD can cause diarrhea, severe abdominal pain and cramping, nausea and vomiting, reduced appetite, and weight loss.
- IBD is treated with various classes of drugs, including aminosalicylates, corticosteroids, immunosuppressants and biologics (drugs created through biotechnological methods), or – if drug therapy fails – surgery.

IBD facts

- The prevalence of IBD in Canada is one of the highest in the world: about 233,000 Canadians, or one out of 150, live with the disease (129,000 with CD and 104,000 with UC).
- An estimated 5,900 Canadian children have IBD.
- More than 10,200 new cases of IBD are diagnosed every year.
- The incidence of IBD has risen since 2001, particularly in children under age 10.
- 20-30% of people with IBD are diagnosed before age 20.

Impact of IBD

- Individuals with IBD have a lower quality of life than the general population across all dimensions of health.
- In addition to digestive symptoms, many people living with IBD also frequently experience joint pain (72%), skin problems (42%), and eye inflammation (23%).
- Malnutrition and blood disorders are common in IBD patients; they are typically caused by avoiding specific food items or food groups, either because of existing symptoms or concern that they may bring on symptoms.
- Most IBD patients experience their first hospitalization within two years of diagnosis, and more than half of people with Crohn’s disease eventually require surgery.
- IBD of the large intestine raises the risk of colorectal cancer.
- People with IBD have a lower rate of participation in the workforce; the disease can also impact educational attainment and thus career achievement and income resulting in significant and often underappreciated economic burden.
• Costs attributable to IBD in Canada totalled $2.8 billion in 2012, of which direct medical costs accounted for $1.2 billion and indirect costs (opportunity losses) $1.6 billion.

• IBD also impacts caregivers, who often need to be actively involved in patients’ care and may experience “caregiver burnout.”

**Gaps in IBD care**

- Public awareness of the symptoms of, and risk factors for, IBD is low. Further, the lingering stigma of digestive problems can prevent people from seeking necessary medical attention.

- Because IBD is not considered preventable, it is not included in government-funded chronic disease prevention policies or educational campaigns.

- Awareness among primary care physicians is also inconsistent, which may impede diagnosis.

- Access to and quality of care for IBD vary considerably across the country.

- Two-thirds of patients with clinically significant IBD wait more than 18 weeks for treatment; the Canadian Association of Gastroenterologists recommends a maximum of 2 weeks.

- Adherence to treatment among IBD patients is inconsistent.

- No publicly funded services exist for people with IBD and their caregivers.

**Evidence-based solutions**

- The chronic nature of IBD and the need for ongoing patient monitoring align with multidisciplinary management.

- Key opinion leaders in Canada and elsewhere agree that a multidisciplinary team is the most effective structure for managing IBD; the IBD Standards Group, a consortium of U.K. medical and nursing associations, recommends a multidisciplinary team that includes IBD nurse specialists.

- IBD patient surveys indicate that patients also favour a multidisciplinary team approach.

- The IBD nurse specialists represents a valuable component of the multidisciplinary care team; these specialists are currently scarce in Canada.

- Further research is needed to determine how IBD nurse specialists might increase access and efficiencies in IBD care delivery.

- Roles of IBD nurse specialists range from the provision of expert clinical care to education, research, consultancy and service management.

- Delivery of IBD care is enhanced by an IBD case manager, who coordinates the flow of care and ensures consistent patient monitoring and support.

- The creation of IBD Centres of Excellence (CoEs) organized around three pillars of excellence – patient care, research and education – can facilitate the flow of information about best practices, help define benchmarks for excellence, and address gaps in current care.

- An IBD Consortium can serve as a centralized vehicle for developing individual CoEs across the country and transmitting information across CoEs.
**Recommendations**

Having reviewed the current status of IBD care in Canada and the global literature on best practices, the Canadian Digestive Health Foundation recommends:

- Recognition of IBD as a **chronic disease** and **national health priority**
- More **funding and resources** allocated to IBD
- Creation of an IBD **Consortium** to facilitate and harmonize the development of individual **IBD Centres of Excellence**
- Adoption of a **multidisciplinary team** approach to the treatment of IBD, in the Centres of Excellence and elsewhere throughout the country
- More strategic use of multidisciplinary team members, including **IBD nurse specialists**, and more research to corroborate best practices within the team model
- **Data collection and measurement** to establish value and further enhance efficiencies.

The proposed recommendations would help create the infrastructure needed to enable timely and equitable access to services, promote best practices, and deliver more efficient and cost-effective care. Adopting the recommendations will help Canada provide the highest standard of care for its large community of people with IBD, significantly improve their quality of life, and propel our country to a position of international leadership in IBD.
Introduction

Inflammatory bowel disease (IBD) is a serious and underrecognized health concern.

Inflammatory bowel disease (IBD) is a group of disorders that has two main forms: ulcerative colitis (UC) and Crohn's disease (CD). It affects hundreds of thousands of Canadians – often in their most productive, energetic years – and seriously compromises their education, productivity, participation in the workforce, relationships and overall quality of life.

Most Canadians are well aware of the devastating impact of such well-known diseases as diabetes and cancer. IBD places no less of a strain on individuals, their families and the health care system. Both Crohn's disease and ulcerative colitis are lifelong diseases for which there is currently no cure. To manage their symptoms, most patients require a regimen of strong and often expensive medications, and many eventually need surgery. IBD also puts patients living with the disease at higher risk of developing colorectal cancer and dying prematurely.

While Canada has a solid base of expertise in IBD care, we lack an integrated framework that would enable us to deploy best practices across the country. Research from several countries has shown that multidisciplinary teams offer the highest level of care for virtually all chronic diseases, including IBD. We need to develop such teams more widely and systematically throughout the country. Moreover, such teams need to make greater use of specially trained IBD nurses, who can safely and cost-effectively carry out many of the functions required to care for IBD patients.

Gastroenterologists – the specialist physicians responsible for caring for most IBD patients – are in short supply nationwide. A multidisciplinary approach that makes strategic use of IBD nurses makes clinical, logistical and health-economic sense.

To make the multidisciplinary model a reality across Canada, we need to recognize IBD as a chronic disease, make it a national priority, and set up a centralized consortium of expertise to help guide IBD clinics toward becoming centres of excellence.

As a chronic and often debilitating disease, IBD places inordinate demands on patients, their families and the healthcare system. An integrated framework for IBD care will not only increase the quality of care, but will increase efficiencies in the delivery of care and create synergies in research, measurement and education. We urgently need a systematic, centralized approach to improving care for IBD. It is the only way forward.
Understanding IBD

IBD involves chronic inflammation of all or part of the digestive tract. The disease encompasses two separate disorders that cause inflammation and ulceration of the small and large intestines: ulcerative colitis (UC) and Crohn’s disease (CD). IBD can be painful and debilitating, and may even lead to life-threatening complications.\(^1\) While it tends to cluster in families, in most cases there are no affected relatives.

**Ulcerative colitis**

UC typically affects only the innermost lining of the large intestine (colon) and rectum and occurs through continuous stretches of the digestive tract. Symptoms, which usually develop gradually, include:\(^2\)

- Severe and bloody diarrhea
- False urges to have a bowel movement
- Abdominal pain and cramping
- Nausea and vomiting
- Decreased appetite
- Weight loss
- Mild fever
- Anemia
- Loss of body fluids

In a significant minority of patients, UC also causes symptoms outside the digestive tract, such as arthritis, osteoporosis, and uveitis.\(^3\)

The disease develops most frequently between the ages of 15 and 40, with a second peak in incidence between 50 and 80, and its cause is poorly understood.\(^3\) It occurs less often than average in current smokers, but former smokers appear to be at increased risk.\(^3\) While UC is a life-long disease, the inflammation tends to wax and wane. Many affected people have periods of active symptoms alternating with pain-free remission periods.

**Crohn’s disease**

CD can cause inflammation anywhere in the digestive tract, from mouth to anus, but typically affects the lower part of the small intestine and the upper part of the colon. The ulcerations may spread deep into the affected parts of the digestive tract. Diseased sections of bowel are often interspersed with healthy ones.
CD can range from mild to severe and may develop gradually or come on suddenly, without warning. Symptoms, which vary widely depending on the location(s) of disease along the digestive tract, may include:

- Abdominal pain
- Cramping
- Diarrhea
- Nausea
- Vomiting
- Reduced appetite
- Weight loss

While CD can occur at any age, most people are diagnosed before age 30. Risk factors include family history, smoking, Eastern European Jewish descent, and living in cities and industrialized nations. It is not known what actually causes the disease in susceptible people, though researchers believe something triggers the immune system to mistakenly attack harmless or beneficial bacteria, foods, and even the body's own tissues. A lifelong disease, CD typically follows a pattern in which periods of acute flare-ups alternate with periods of remission.

CD can cause inflammation anywhere in the digestive tract, from mouth to anus.

### Ulcerative colitis vs. Crohn's disease: Similarities and differences

<table>
<thead>
<tr>
<th>Attribute</th>
<th>Ulcerative colitis</th>
<th>Crohn's disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>Risk factors</td>
<td>Former smoking</td>
<td>Smoking, family history, geographical location, ethnicity</td>
</tr>
<tr>
<td>Age of onset</td>
<td>Two diagnosis peaks: 15-40 and 50-80</td>
<td>Usually before 30</td>
</tr>
<tr>
<td>Pattern of onset</td>
<td>Typically gradual</td>
<td>Gradual or sudden</td>
</tr>
<tr>
<td>Chronicity</td>
<td>Lifelong</td>
<td>Lifelong</td>
</tr>
<tr>
<td>Pattern of inflammation</td>
<td>Continuous along a portion of the GI tract, always involving the rectum</td>
<td>Alternating diseased and healthy segments</td>
</tr>
<tr>
<td>Depth of inflammation</td>
<td>Usually present only in the inner lining of the intestine</td>
<td>Ulcers can penetrate the entire thickness of the intestinal lining</td>
</tr>
<tr>
<td>Bleeding</td>
<td>Common during bowel movements</td>
<td>Uncommon</td>
</tr>
<tr>
<td>Location of pain</td>
<td>Typically in lower left abdomen</td>
<td>Typically in lower right abdomen</td>
</tr>
</tbody>
</table>
Treating IBD

The goals of IBD therapy are to eliminate symptoms, prevent flare-ups, and restore quality of life. Medications control symptoms and promote healing in most patients. Surgery may be warranted if medications fail to control symptoms, if precancerous changes occur in the colon, and for some serious complications.

Four basic categories of drug are currently used to treat IBD, and some patients also benefit from antibiotics:

- **Aminosalicylates**: these drugs, which contain 5-aminosalicylic acid (5-ASA), are effective for treating mild-to-moderate IBD flare-ups as well as maintaining remission. Recent evidence suggests they are more effective for UC than for CD.

- **Corticosteroids**: These fast-acting and potent anti-inflammatory drugs are a mainstay of treatment for acute flare-ups. Their side-effect profile makes long-term use or repeated short-term use unadvisable.

- **Immunomodulators**: These drugs decrease the inflammatory response by modifying the activity of the immune system. Immunomodulators are appropriate for patients who do not respond to 5-ASA or steroids, have steroid-dependent disease, or need to maintain remission.

- **Biologic drugs**: Engineered through biotechnology methods and often isolated from natural sources (human, animal or microorganism), these drugs decrease inflammation by targeting specific molecular pathways that are abnormal in people with IBD.

- **Antibiotics**: Antibiotics are effective in CD patients with bacterial infections, abscesses and fistulas (abnormal channels between sections of intestine or between the intestine and another part of the body). Some researchers also believe antibiotics can help control IBD symptoms by reducing intestinal bacteria.

References


IBD in Canada and the World

By and large, IBD is considered a disease of the developed world, particularly Europe and North America. As developing nations become more industrialized, the prevalence (number of reported cases) and incidence (number of new cases) of IBD tend to increase. In Canada, the disease is as common as Type 1 diabetes and epilepsy and more than twice as common as multiple sclerosis or Parkinson’s disease.

According to a 2012 Crohn’s and Colitis Foundation of Canada report titled, The Impact of Inflammatory Bowel Disease in Canada, approximately 233,000 Canadians live with IBD. This translates to one out of every 150 Canadians or 0.7% of the population. An estimated 5,900 children have IBD, and the prevalence in this group is climbing. Slightly over half of affected patients (129,000) live with CD and the remainder (104,000) have UC.

These figures place Canada among the countries with the highest prevalence and incidence rates of IBD in the world. Equally concerning, the prevalence of IBD in Canada has risen significantly since the 2008 figure of 201,000. Using information acquired from the Régie de l’assurance maladie du Québec, researchers have also learned that the prevalence of CD more than tripled in Québec between 1993 and 2002. This trend is not confined to Canada alone: a number of European and North American countries have experienced a doubling in new cases of CD in the four decades between 1955 and 1995.

While the Canadian incidence of IBD may have finally reached a plateau, the prevalence is expected to keep rising as more Canadians live longer with chronic conditions.
For reasons that are still poorly understood, the frequency of IBD diagnoses varies widely among countries. For example, the Canadian incidence rate of Crohn’s disease – about 15 new cases per 100,000 people – dwarfs the Croatian figure of 0.7 per 100,000.²

**References**


Impact of IBD

Health and quality of life

Individuals with IBD have a lower quality of life than the general population across all dimensions of health; UC and CD have a comparable effect on quality of life.¹ Not surprisingly, those with more active disease experience the greatest reductions in quality of life. However, even people without symptoms suffer from distress, anxiety and fear.¹

In addition to their digestive symptoms, many people living with IBD also frequently experience joint pain (72%), skin problems (42%), and eye inflammation (23%).²

Most IBD patients experience their first hospitalization within two years of diagnosis,¹ and more than half of people with CD eventually require surgery.³ IBD may also increase susceptibility to other illnesses and lead to complications such as cancer (see box below).

Women with active IBD, particularly CD, may have problems with fertility, especially if they are underweight or eating poorly.⁴

THE CANCER CONNECTION

Colorectal cancer, which represents the major cause for excess morbidity and mortality in IBD, occurs in 5 to 13% of patients with UC and 0.4-0.8% of patients with CD. Established risk factors include long duration of the disease, large extent of disease, low disease activity, young age at onset, presence of certain complications (e.g., stenotic disease), presence of certain other diseases (e.g., primary sclerosing cholangitis), and possibly inadequate surveillance and/or drug therapy.⁵

Productivity

People with IBD have a lower rate of participation in the workforce than the general population.¹ Among Canadians with CD who do work, current evidence suggests that some are taking premature retirement.¹ This is hardly surprising, when one considers that two-thirds of respondents in a European study of over 5,000 IBD patients reported that their symptoms affected their ability to perform at work.⁶

Of particular and sometimes overlooked significance is that IBD is often diagnosed in adolescence or early adulthood, which can impact educational attainment as well as career selection,¹ and thus socioeconomic status and income. As such, IBD affects not only patients’ health but their careers, relationships, hopes and dreams.
**Economic burden**

A conservative estimate of the total costs attributable to IBD in Canada in 2012 yielded a figure of $2.8 billion, which equates to $11,900 per affected person.¹

Direct medical costs, which totalled over $1.2 billion per year, were distributed between medications ($521 million), hospitalizations ($395 million) and physician visits ($132 million). Because CD incurs more frequent hospitalizations and greater use of expensive drugs than UC, CD accounts for a greater slice of the IBD cost pie.¹

Indirect costs of IBD, which include opportunity losses to individual patients and to society, totalled over $1.6 billion in 2012. Long-term work losses eroded an estimated $979 million from the labour force, while short-term work absences chipped away a further $181 million. Patients’ out-of-pocket expenses, the third main contributor to indirect costs, totalled $300 million. Caregiver costs must also be considered: parents who care for children with IBD incur annual costs of $7 million for their efforts, and the costs of caring for severely ill IBD sufferer have been estimated at 32 million per year.¹

Depending on their medical needs, individual patients may incur out-of-pocket expenses such as ostomy supplies, home modifications, formal care, and travel for medical appointments, among others.¹ Even patients with private health plans often face significant co-pays for expensive medications. There are precious few alternatives for these patients, which can further compromise their health.

**Impact on caregivers**

Caregivers need time to accompany IBD patients to medical appointments, stay with or visit them in hospital, and care for them at home. These duties not only take time and energy, but can take a severe toll on psychological well-being – the well-known phenomenon of “caregiver burnout.” Parents are particularly vulnerable to these stresses: in pediatric cases of IBD, at least one parent needs to be actively involved in caring for the affected child, which could lead to up to 7 missed days of work per year.¹ Like patients themselves, caregivers may find their careers and life ambitions curtailed because of their responsibilities.

**References**


Gaps in IBD Care

Public awareness

IBD is underreported in the general media, leading to inconsistent public awareness of symptoms. Further, many individuals view their digestive troubles as embarrassing, shameful, or a sign of personal weakness. The lingering stigma associated with IBD and digestive disease in general can prevent people from seeking appropriate medical attention.1

Because IBD is not considered preventable, it is not included in government-funded chronic disease prevention policies or public health awareness campaigns that target prevention and management of chronic diseases.1

Physician awareness

Lack of awareness extends to the primary care community and emergency departments, which may impede timely diagnosis.1 Physicians who began practicing when IBD was less prevalent than today may lack experience with the disease. In fact, evidence suggests that late diagnosis, inappropriate investigation, and inappropriate management are substantial problems in IBD.1

A Canadian/European survey also found that physicians significantly underestimated the effect of UC on quality of life compared to patient self-reports.1 It appeared the physicians did not fully appreciate the impact of the disease and the significance of specific symptoms to patients.

Diagnostic dilemma

In the fall of 2011, the Crohn’s and Colitis Foundation of Canada conducted a survey of more than 500 patients. Before their diagnosis, respondents were told by medical professionals that they likely had:2

- An eating disorder – 14 per cent
- A mental disorder – 23 per cent
- Irritable bowel syndrome – 48 per cent
- A parasite – 19 per cent
- Food allergies – 30 per cent
- Other (including cancer and pregnancy) – 41 per cent

Access to care

Access to and quality of care for IBD vary considerably across the country. IBD patients in rural communities often have more limited access to diagnostics, professional services and quality care. They also face costs (such as gas, food and accommodations) their more centrally located counterparts do not, which may discourage them from seeking the care they would need.
Irrespective of geographical location, patients are likely to wait a long time for specialist consultations. Faced with an aging population and bottlenecks in accessing screening and diagnostic technology, gastroenterologists are unable to meet the current need for specialist care. As shown in the table below, wait times for conditions suggestive of IBD fall markedly short of the targets set by the Canadian Association of Gastroenterology (CAG) – and are getting longer.

<table>
<thead>
<tr>
<th>Condition/Procedure</th>
<th>Recommended maximum wait time</th>
<th>Median referral to consultation (days)</th>
<th>Median consultation to treatment (days)</th>
<th>Total median wait time (days)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical features of significant active IBD</td>
<td>Within 2 weeks</td>
<td>60</td>
<td>45</td>
<td>106</td>
</tr>
<tr>
<td>Bright red rectal bleeding</td>
<td>Within 2 months</td>
<td>37</td>
<td>14</td>
<td>57</td>
</tr>
</tbody>
</table>

Among the findings in a 2009 report titled Unfinished Business: A Report Card on Wait Times in Canada, one of the most alarming was that 67 percent of patients with clinical features of significant active IBD waited more than 18 weeks before receiving treatment – a sharp deviation from the 2 weeks recommended by the CAG. Similarly, 43 percent of patients with bright red rectal bleeding waited more than 18 weeks before treatment, in contrast to the recommended maximum of 2 months.

These bottlenecks stem, in large part, from the shortage of gastroenterologists across the country – a problem set to become still more pronounced as those in current practice retire at a greater rate than the influx of new entrants to the field.

Access to endoscopy and radiology also varies significantly across regions, making it difficult for some Canadian IBD patients to receive timely assessments and care. Similar variations exist among provincial formularies in coverage of expensive IBD medications, which may force some patients who do not have private coverage into otherwise avoidable surgery.

**Adherence**

The Manitoba Inflammatory Bowel Disease Cohort Study, a population-based study of multiple determinants of health outcomes in IBD, characterized about a third of respondents as “low adherers” to treatment. Adherence rates tended to be lower in patients who faced self-reported obstacles to medication use. Research has consistently linked successful management of chronic diseases to adherence to treatment. By the same token, poor adherence virtually guarantees a less-than-optimal outcome.

Forgetfulness, disease denial, lack of perceived benefit of treatment, poor physician interaction style, insufficient support and information, quantity of medications, complicated dosing schedule, side effects or fears of side effects are all barriers to patient adherence.
Caregiver issues

Caregivers of IBD patients – especially parents of children with the disease – have an acute need for support. The stress of accompanying patients to doctor appointments, missing time at work, and worrying about their affected loved ones takes its toll over time, often leading to the well-documented phenomenon of “caregiver burnout.” At present, however, no publicly funded services exist for people with IBD and their caregivers.¹

References


The IBD Integrated Multidisciplinary Team

In its 2009 report Preventing Chronic Diseases: A Vital Investment, The World Health Organization identified a multidisciplinary team as “a highly effective approach to improving chronic disease care.” As a chronic, lifelong disease, IBD requires interventions at numerous points and levels of the healthcare system. Key opinion leaders in Canada, the U.K. and elsewhere agree that a multidisciplinary team is the most effective structure for managing IBD.

The six IBD care standards developed by The IBD Standards Group, a consortium of specialty medical and nursing associations in the U.K., strongly endorse this philosophy. The first three of these standards, summarized below, recommend the following model of care delivery:

- **Standard A:** High-quality clinical care delivered by a multidisciplinary team that includes IBD nurses
- **Standard B:** Local delivery of care (with rapid access to specialized services as needed)
- **Standard C:** Maintaining a patient-centred service that is responsive to individual needs.

The advent of IBD nurses is a recent development. Given the chronic nature of IBD, the importance of disease-specific and self-management education, the need to fine-tune therapy and encourage drug compliance, and the need to monitor patients for colorectal cancer (a risk of IBD), involvement of IBD nurses in the multidisciplinary team is a logical step.

Within the context of the pan-Canadian shortage of gastroenterologists and the regional inequities in timely access to quality care, the IBD nurse can be a resource-sparing and cost-effective member of the IBD team. Further Canadian research is needed to establish the best use of IBD nurses in this country.

**Components of the team**

The U.K.-based IBD Standards Group recommends that the IBD team include the following members:

- Consultant gastroenterologist (physician specializing in the digestive system)
- Consultant colorectal surgeon
- Clinical nurse(s) with an identified role and competency in IBD
- Clinical nurse(s) with an identified role and competency in stoma therapy and pouch surgery
- Dietitian allocated to gastroenterology
- GI pathologist (physician specializing in cellular abnormalities) with special interest in gastroenterology
- Radiologist with special interest in gastroenterology
- Pharmacist with special interest in gastroenterology.

The U.K. Standards Group further recommends that the IBD team have a designated lead member or central coordinator – a role that falls easily within today’s nursing professionals’ scope of practice.

This list represents an ideal configuration. Minimum requirements in Canada might include a gastroenterologist, colorectal surgeon, IBD nurse, dietitian, GI pathologist, and radiologist, all available for consults as needed.
According to the Standards Group, supportive services, to be used in response to individual patient needs, should include:

- Psychologist and/or counsellor
- Ophthalmologist
- Obstetrician
- Consultant pediatrician with special interest in gastroenterology
- Link with primary care physician (PCP) to provide an educational role with local PCPs.

In some jurisdictions in Canada, the support team may also require a psychiatrist to prescribe medications such as antidepressants. Other ancillary health providers to consider include social workers and physiotherapists. Administrative support for getting medication coverage is also essential.

The IBD nurse

The specially trained IBD nurse understands the pathogenesis and presentation of IBD, has an up-to-date knowledge of treatment options, appreciates the role of nutrition in IBD management, and can draw on this knowledge to formulate and/or discuss treatment plans with patients. More general skills include the ability to work with and supervise other people, strong organizational skills, and a proactive working style to identify needs and participate in developing solutions.

In its 2013 consensus statement, N-ECCO – a European organization devoted to improving access to nurse education in IBD – describes the advanced IBD nurse as “an autonomous clinical expert in IBD who is responsible for the assessment and provision of evidence based care planning, and treatment evaluation, and who provides practical information, education and emotional support for patients with IBD.”

Today’s IBD nurses play more than an ancillary role. By conducting assessments, procedures and surveillance, educating and monitoring patients, and acting as gatekeepers within the IBD care team, these health care professionals assist gastroenterologists’ clinical load and inject considerable efficiencies into the delivery of IBD care.

Depending on their work setting and local clinic needs, IBD nurses may take on the following duties (pending regulatory approvals and education), among others.

<table>
<thead>
<tr>
<th>Clinical</th>
<th>Patient &amp; systems management</th>
<th>Educational/supportive</th>
<th>Research &amp; advocacy</th>
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<tbody>
<tr>
<td>・ Assess patients (including history and physical exam)</td>
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<tr>
<td>・ Order and interpret diagnostic tests for IBD (NPs)</td>
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<tr>
<td>・ Prescribe treatment (NPs)</td>
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<tr>
<td>・ Monitor response to treatment and alter treatment as needed to induce or maintain remission</td>
<td></td>
<td></td>
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<tr>
<td>・ Administer and monitor immunomodulator or biologic therapy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>・ Triage community referrals</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>・ Manage newly diagnosed patients</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>・ Help run follow-up clinics</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>・ Develop and define IBD services</td>
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<td></td>
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<tr>
<td>・ Act as “gatekeeper” within the multidisciplinary team</td>
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<tr>
<td>・ Coordinate colorectal cancer surveillance</td>
<td></td>
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<td></td>
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<tr>
<td>・ Help transition adolescents to adult services</td>
<td></td>
<td></td>
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<tr>
<td>・ Provide education and counselling</td>
<td></td>
<td></td>
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<tr>
<td>・ Provide nutritional support</td>
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<td></td>
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<tr>
<td>・ Provide inpatient support</td>
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<tr>
<td>・ Run telephone advice lines</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>・ Conduct clinical IBD research</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>・ Serve as patient advocates</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>・ Raise awareness of IBD in the community</td>
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</tbody>
</table>
Not to be discounted, IBD nurses provide that essential element of caring that enables patients to cope with their chronic disease. This empathetic support is as clinically meaningful an endpoint as the execution of a technical procedure. As “front liners” in care, IBD nurses also have a unique vantage point from which to advocate for patients. In fact, the European N-ECCO consensus statement lists advocacy as one of their core responsibilities:

“Nursing involves advocacy for all patients and is of the utmost importance to patients with IBD due to the complex, uncertain and chronic nature of the condition. Advocacy for IBD patients includes identifying their needs and ensuring appropriate access to specialist care.”

**Levels of nursing professional that can fulfill the role of an IBD nurse**

Depending upon local resources, regulations and culture, several levels of nursing professionals can fulfill the role of an IBD nurse. Nursing professionals in Canada fall under four broad categories:

<table>
<thead>
<tr>
<th>Licensed practical nurse (LPN):</th>
<th>Registered nurse (RN):</th>
</tr>
</thead>
<tbody>
<tr>
<td>Has a 2-year college diploma</td>
<td>Has graduated from an accredited nursing school or university</td>
</tr>
<tr>
<td>Has passed the Canadian Practical Nurse Registration Exam</td>
<td>Has successfully completed the Canadian Registered Nurse Exam</td>
</tr>
<tr>
<td>Manages chronic stable patients</td>
<td>Manages acute and chronic health conditions</td>
</tr>
<tr>
<td>May provide some medication management depending on training and jurisdiction</td>
<td>Conducts full physical assessment as required</td>
</tr>
<tr>
<td>Reinforces health education and medication management</td>
<td>Monitors drug therapy</td>
</tr>
<tr>
<td>Provides all levels of patient education, including medication therapy</td>
<td>Provides all levels of patient education, including medication therapy</td>
</tr>
<tr>
<td>Educates staff</td>
<td>Educates staff</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Clinical Nurse Specialist (CNS):*</th>
<th>Nurse practitioner (NP):*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Has a Master’s degree</td>
<td>Has a Master’s degree</td>
</tr>
<tr>
<td>Provides expert nursing care for specialised client population</td>
<td>Can carry out all the duties and responsibilities of the CNS role</td>
</tr>
<tr>
<td>Develops clinical practice guidelines and protocols</td>
<td>Provides direct evidence-based care in the areas of health promotion, treatment, and management of health condition</td>
</tr>
<tr>
<td>Provides direct evidenced-based clinical care</td>
<td>Is a registered nurse with additional education, preparation and experience</td>
</tr>
<tr>
<td>Functions as an advanced nurse educator</td>
<td>Can autonomously diagnose, interpret diagnostic tests, and prescribe medication</td>
</tr>
<tr>
<td>Conducts independent research</td>
<td>Can perform specific procedures within the scope of practice</td>
</tr>
<tr>
<td></td>
<td>Works in collaboration with physicians</td>
</tr>
</tbody>
</table>

* Note: CNS and NP fall under the umbrella term Advanced Practice Nurse (APN), a designation used for registered nurses with a Master’s level education.
Training for IBD nurses in Canada

The Canadian Nurses Association provides training for a number of specialties, including gastroenterology. To obtain a specialist designation, nurses have to pass a specialty certification exam and maintain their certification through continuing education or rewriting the exam. Specialty nurse training courses focused on IBD are available in various parts of the world.

Where Canadian IBD nurses are located

IBD nurses are scarce in Canada. By current estimates, hospitals and clinics throughout the country employ under 20 IBD nurses, respectively located in Newfoundland, Nova Scotia, Quebec, Ontario, Saskatchewan, Alberta, and British Columbia. Most IBD clinics do not have a nurse with specialized knowledge of IBD as part of their interdisciplinary team.

A larger number of IBD nurses are funded by pharmaceutical companies rather than health service organizations. They serve as an important resource, but under ideal conditions the health system would provide funding to ensure lack of bias and equitable access to nursing resources for all patients with IBD. It is also worth noting that private investment from pharmaceutical companies is subject to change when drug patents expire and corporate revenues fluctuate.

The IBD Case Manager

The rationale for this position, which would be an appropriate role for an IBD nurse, is to provide consistent and proactive monitoring of patients on immunomodulator or biologic therapy. The role entails:

- Knowledge of the pharmacology and side effects of the immunosuppressive and biologic drugs taken by IBD patients
- Ability to communicate this knowledge to patients and other health care providers
- Coordination of laboratory testing schedules and monitoring of results
- Understanding of surveillance protocols to enable communication about adverse events to appropriate personnel
- Keeping drug authorization paper work up to date to ensure uninterrupted therapy
- Psychological support

References

Impact of IBD Nurses on IBD Management

Patients with chronic diseases readily embrace – indeed, welcome – the paradigm of multidisciplinary care. Increasing evidence suggests that specially trained nurses can perform as safely and effectively as doctors across a range of conditions and procedures. Most of this evidence comes from other parts of the world, as the small number of IBD nurses in Canada has placed limits on research output in this area.

Clinical effectiveness

Royal College of Nursing audit

The Royal College of Nursing (RCN), the association representing the nursing profession in the U.K., conducted a two-week audit to collect definitive data on the role and activity of nurses with specialized training in IBD care. IBD nurse specialists. Results of the audit appeared in the 2012 RCN report Inflammatory Bowel Disease Nursing: results of an audit exploring the roles, responsibilities and activity of nurses with specialist/advanced roles.

The following insights from the report highlight the influential roles played by IBD nurses in the delivery of care to IBD patients:

- IBD nurses influence the management of considerable numbers of patients. Over the two-week audit period, they took over 6,000 calls through telephone advice lines, saw more than 3,000 outpatients and more than 100 inpatients, and consulted over 1,000 patients at specialized nursing services. These figures add up to almost 30,000 interactions per year.
- Significant numbers of nurses run autonomous nurse clinics and other advanced practices.
- IBD nurses play pivotal roles in complex drug management; most of the nurses screen, counsel, and monitor IBD patients on drug treatment.

Specialty nurses and GI procedures

In one U.S. study, there was no difference in the pick-up rate of adenomas and carcinomas between nurse-led and physician-led endoscopy. Of note, significantly more of the nurses’ patients returned for repeat screening after one year. The investigators concluded that “If nurses performed screening examinations, more patients could be screened and, at current income levels, at a lower cost.” Similarly, a randomized controlled trial comparing doctors with nurses in the execution of flexible sigmoidoscopy, conducted at the National Naval Medical Center in Bethesda, found no differences in polyp miss rate (20% in each case). No complications occurred in any patient.

Cost efficiencies

The use of IBD nurses to carry out roles for which they have been specially trained makes obvious health-economic sense: it alleviates the burden on gastroenterologists and primary care physicians while enabling a high level of continuity, thus streamlining the flow of care and minimizing bureaucratic inefficiencies. Studies have shown that specialist nursing roles can reduce referral times, length of hospital stays, and risks of patient complications. In an Australian study, a multidisciplinary IBD service including routine nurse follow-up through a health line significantly reduced healthcare utilization and disease burden.

Within Canada, a Halifax analysis demonstrated a 50% reduction in patient wait times for IBD care following the introduction of an urgent access clinic led by an IBD nurse practitioner (unpublished data). Patients reported that attending the nurse-led clinic enabled them to avoid a more costly visit to the emergency room.
Canadian survey data

The Hamilton Health Sciences experience

In 2011, the McMaster University Medical Centre [part of Hamilton Health Sciences] IBD clinic conducted a pilot project using an interdisciplinary IBD team consisting of 4 gastroenterologists (GIs), 1 colorectal surgeon, 2 psychiatrists, 1 NP and 1 registered dietitian. Complex patients attended half-day clinics with a GI and NP. An interdisciplinary clinic for surgical, psychiatric and nutrition consultation was available once a month. Patients requiring urgent access (as determined by the NP) were provided with a contact number during disease relapse.

In all, 178 patient appointments were scheduled in 33 half-day clinics over 10 months. Reasons for the visits included:

- IBD exacerbations (28%)
- Psychiatric counselling (20%)
- Nutritional counselling (17%)
- Discussions of change in medical management (15%)
- Urgent follow-up after recent hospitalization (8%)
- Pregnancy-related issues of poor weight gain (3%)
- Multiple complex fistulae and failed medical therapy (remainder – about 9%)

Patients expressed as much satisfaction with this model of care delivery as with the traditional physician-centred model. Investigators concluded that “patients are accepting a shift from limited access to a primary GI to a team approach which includes a NP. Having prompt access during relapse and an interdisciplinary team approach...may improve patient outcomes.”

CDHF IBD Survey

In 2013, the Canadian Digestive Health Foundation conducted a survey to assess how gastroenterologists’ perceptions of patient priorities and self-reported patient priorities match up. Patients and physicians agreed on the importance to patients of achieving remission and returning to a normal lifestyle. However, they differed in their perceptions of patients’ reliance on IBD nurses to discuss concerns about symptoms and treatment: gastroenterologists believed their patients confided most readily in nurses, while patients themselves placed the greatest value on communicating with their gastroenterologists. (It should be noted that many of the surveyed patients did not have access to IBD nurses and were thus not in a position to use them as a resource.) As IBD nurses become more visible and their role continues to evolve, it is reasonable to expect that patients will become increasingly comfortable confiding in them about all aspects of their care. To put it another way, patients need to be educated to fully appreciate the role of the IBD nurse.

In support of the multidisciplinary IBD management model, both patients and physicians strongly agreed on the importance of the distinct role of each member within the multidisciplinary team.
Taking Steps to Introduce an Integrated Multidisciplinary Patient-Centric Care Model

Current gaps and needs

One of the major obstacles to the use of IBD nurses is the scarcity of research to measure outcomes of nurse-led models of care, leading to underfunding and underuse of IBD nursing professionals in Canada. The U.K. Standards Group’s recommended number of IBD nurses brings the Canadian shortage to light. As a “minimum viable” allotment, the Group recommends three full-time IBD nurse equivalents for a population of 250,000. For Canada’s population of approximately 35,000,000, this translates to 420 IBD nurses — several times more than the number actually practicing in the country. Of course, Canada needs to keep abreast of changes in international models and follow suit if the changes are applicable to this country.

As described earlier, IBD nurses have broadened their scope and reach in some parts of the world. In Canada, however, IBD nurses still face systemic challenges on several fronts. Nurses themselves have identified the following challenges in caring for IBD patients:

- Lack of knowledge of IBD by some health professionals
- Inconsistent access to members of a multidisciplinary team
- Difficulty communicating with patients; variant styles of information delivery that affect understanding and acceptance
- Lack of ongoing formal education and access to educational resources
- Lack of time to share information with patients
- Lack of clerical support (leading to time shortages)
- Inconsistent patient adherence to treatment and lifestyle recommendations of health professionals
- Poor management of depression and stress in the IBD population, coupled with lack of psychological and/or psychiatric support.

**CASE STUDY**

Usha Chauhan, NP, McMaster University Medical Centre IBD Clinic

<table>
<thead>
<tr>
<th>Presentation</th>
<th>How the NP managed the case</th>
<th>Patient outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>A 21-year-old patient had CD intolerant to immunomodulators</td>
<td>Saw patient on 3 occasions</td>
<td>Had course of budesonide (steroid)</td>
</tr>
<tr>
<td>Had elevated platelets and inflammatory markers</td>
<td>Informed patient she would discuss the visits with the clinic gastroenterologist</td>
<td>Agreed to have repeat colonoscopy</td>
</tr>
<tr>
<td>Wanted to use marijuana as therapy for pain</td>
<td>Made appointment for the patient with clinic psychiatrist</td>
<td>Started biologic therapy</td>
</tr>
<tr>
<td>Wanted her gastroenterologist to sign a special access form so she could grow her own marijuana</td>
<td>Asked patient to read articles from reputable websites on marijuana use and IBD</td>
<td>Stopped using marijuana for pain</td>
</tr>
</tbody>
</table>
Along similar lines, the literature on IBD nursing has uncovered the following needs:\textsuperscript{2,5,6}

- Need to develop a formal, standardized system whereby nurses can acquire a nationally recognized education in both gastroenterology and IBD
- Increased use of distance communication to reduce clinical appointments while ensuring that patients receive timely attention
- Administrative support to allow the nurses to spend more time with patients.

Multidisciplinary teams have been gaining ground in just about all health disciplines and appear to be the way of the future. Given appropriate scope and support, IBD nurses have the opportunity to add substantial benefits and efficiencies to the teams involved in caring for IBD patients.

References

**IBD Centres of Excellence**

While the standard of IBD care in Canada is comparatively high and the country already has a strong research tradition, there is much room for improvement. A framework for sharing best practices across the country would help define benchmarks for excellence and address gaps in current care.

The Centre of Excellence (CoE) is a powerful vehicle for facilitating this flow of information. CoEs have already demonstrated their potency in many areas of medicine, including allergy and immunology, arthritis, stroke, and stem cell research. As a chronic, complex disease requiring sophisticated treatment, IBD would lend itself especially well to the CoE model.

As detailed below, CoEs are organized around three pillars of health care excellence: patient care, research and education. By serving as central repositories of IBD expertise, CoEs catalyze the cross-pollination of ideas, generate efficiencies in research and data collection, and allow for consistent messaging.

<table>
<thead>
<tr>
<th>The Centre of Excellence Model</th>
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<tbody>
<tr>
<td><strong>Patient care</strong></td>
</tr>
<tr>
<td>• Central triaging allows patients to be served based on need</td>
</tr>
<tr>
<td>• Houses multidisciplinary clinics</td>
</tr>
<tr>
<td>• Generates efficiencies in administration of biologic drug therapy</td>
</tr>
<tr>
<td><strong>Research</strong></td>
</tr>
<tr>
<td>• Guiding principle: “Every patient is a research patient”</td>
</tr>
<tr>
<td>• Brings together various types of research: basic science, clinical, outcomes, population health</td>
</tr>
<tr>
<td>• Allows experts to collaborate to strengthen each other’s work</td>
</tr>
<tr>
<td>• Facilitates measurement of processes and outcomes</td>
</tr>
<tr>
<td><strong>Education</strong></td>
</tr>
<tr>
<td>• Centralized dissemination of information enables “branded” education</td>
</tr>
<tr>
<td>• Allows for control of information</td>
</tr>
</tbody>
</table>

Not all IBD centres will have the resources to excel in all areas. As initial goals, smaller IBD centres can focus on excellence in clinical care, while drawing from the education and research expertise of larger, more established centres.

Within the realm of patient care, CoEs foster a management philosophy that emphasizes:

- Timely assessments
- Treating beyond symptomatic relief (e.g., toward sustained deep remission)
- Adoption of best practices, guidelines and standards
- Consideration of individual patient preferences and needs
- Sharing of information and resources to enhance care.
**Benefits of the Centres of Excellence Model**

By centralizing research capabilities and disseminating best-practice resources to avoid duplication and substandard care, CoEs can yield the following systemic health benefits:

- **Effectiveness**: Health services are based on the most up-to-date scientific knowledge
- **Efficiency**: Resources are optimally used to achieve desired outcomes
- **Safety**: Standardized best practices mitigate risks and harmful effects
- **Acceptability**: Health services are respectful and responsive to user needs, preferences and expectations
- **Accessibility**: Health services are provided in a suitable setting within a reasonable time and distance

For Canadians in remote locations, the CoE can facilitate access to remote care (e.g., telehealth, patient videoconferences), thus saving patients from debilitating flares and easing the cost burden on the healthcare system.

The CoE model also enables the seamless blending of clinical and research capabilities. One of the model’s core tenets is that “every patient is a research patient.” (While many IBD patients welcome the opportunity to participate in research studies, it goes without saying that patients who do not wish to participate should not be pushed to do so.)

**Becoming a Centre of Excellence**

IBD centres in Canada can take defined steps to develop as CoEs:

- Identify where gaps exist
- Address gaps through internal review processes and collaboration with other centres
- Select one area of focus; patient care is suggested as the logical starting point, followed by education and research
- Define a patient-centered philosophy of care
- Establish a multidisciplinary IBD clinic that includes gastroenterologists and other specialist physicians, IBD nursing professionals, biologic drug coordinators, and other health providers (e.g., clinical psychologist, nutritionist); depending on the region, the structure of the multidisciplinary team may include remote care providers
- Establish outcome measures to facilitate review and make adjustments as needed.

**The IBD Consortium**

Key opinion leaders in Canadian gastroenterology have proposed the idea of an IBD “Central Consortium” as a steering group to guide the development of individual CoEs across the country. Such a consortium would facilitate collaboration with government, industry and other funders to help establish CoEs. A consortium would also serve as a hub for transmitting information across CoEs.
Recommendations

Based on the gaps and needs identified in the foregoing discussion, the Canadian Digestive Health Foundation recommends the following integrated framework:
Canada has a wealth of specialist expertise and an existing infrastructure for IBD care. With the infusion of centralized resources and an overarching strategy, the country can establish itself as an international IBD care model.

Centralizing and sharing best-practice resources will help keep IBD patients healthier. This will not only improve the quality of countless lives, but will decrease the burden of IBD on our health system and economy.

We owe it to the community of Canadians affected by IBD to move these recommendations forward. The CDHF calls upon government, industry, the public, and other key stakeholders to take these vital steps.
The Canadian Digestive Health Foundation supports the millions of Canadians who suffer from digestive disorders every year. As the Foundation of the Canadian Association of Gastroenterology, we are directly connected to Canada’s leading digestive health experts, physicians, scientists and other health care professionals. We provide practical, science-based information that is up to date and unbiased. We exist to reduce suffering and improve quality of life by providing trusted, accessible, and accurate information about digestive health and disease by empowering all Canadians to manage their digestive health with confidence and optimism.