The Impact of Inflammatory Bowel Disease in Canada 2018: A Scientific Report from the Canadian Gastro-Intestinal Epidemiology Consortium to Crohn’s and Colitis Canada

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Abstract

Canada has among the highest rates of IBD in the world, and the number of people living with these disorders is growing rapidly. This has placed a high burden on the health care system and on the Canadian economy—a burden that is only expected to grow in the future. It is important to understand IBD and its impact on Canadian society in order to appropriately plan for health care expenditures, reduce the burden on patients and their families, and improve the quality of life for those afflicted with IBD. In Canada, there is a lack of public awareness of the impact of Crohn’s disease and ulcerative colitis. Raising awareness is crucial to reducing the social stigma that is common with these diseases and to help individuals maximize their overall quality of life. A better public understanding of IBD can also help to raise and direct funds for research, which could lead to improved treatments and, ultimately, to a cure. This report from Canadian clinicians and researchers to Crohn’s and Colitis Canada makes recommendations aimed at the public, policy-makers, scientific funding agencies, charitable foundations and patients regarding future directions for advocacy efforts and areas to emphasize for research spending. The report also identifies gaps in knowledge in the fields of clinical, health systems and epidemiological research.
Inflammatory bowel disease (IBD) is a group of disorders that causes sections of the gastrointestinal tract to become severely inflamed and ulcerated (1). An abnormal response of the body’s immune system plays a role in each of the two main forms of IBD: Crohn’s disease and ulcerative colitis. In the absence of a cure, current therapies are directed at inducing and maintaining remission (2, 3). Most people afflicted with IBD require ongoing medication. When this fails, surgery is often required (4, 5). These are lifelong diseases, usually starting in adolescence or early adulthood in otherwise healthy, active individuals. Crohn’s disease and ulcerative colitis also occur in children, and IBD is increasingly being diagnosed in very young children (under 5 years of age) (6). IBD severely impacts quality of life through ongoing and debilitating symptoms, reduction in the ability to work, social stigma, management of washroom access issues, challenges with physical intimacy, and restrictions in career choices (7, 8).

Crohn’s and Colitis Canada (CCC) has partnered with the Canadian Gastro-Intestinal Epidemiology Consortium (CanGIEC), a national network of researchers and clinicians with expertise in the epidemiology, burden and health system evaluation of IBD. The Canadian Gastro-Intestinal Epidemiology Consortium’s overall aim is to assess the burden of IBD, provide evidence for environmental risk factors of IBD and improve the way that health care systems treat people with IBD, provide evidence for environmental risk factors of IBD and improve the way that health care systems treat people with IBD, and identify areas to emphasize for research spending and gaps in knowledge in the fields of clinical, health systems, and epidemiological research. This report is also aimed at the general public, patients with IBD and stakeholders to help them understand the overall impact of IBD in Canada in 2018.

To undertake this review, a steering committee (EB, CB, AB, GK, GN and SM) was formed, comprised of academic experts in gastroenterology and health system research. The 2018 Impact of IBD in Canada Report was created by working groups corresponding with the following sections in this report: epidemiology (EB, CB, AB, SC and GK); direct costs and health services utilization (EB, EK, LL, SM, GN, HS and LT); indirect costs of IBD care (WE, EK, LL, SM and AW); quality of life in patients with IBD (JJ, GN and AO); special populations: children with IBD (EB, MC, AG, EK, DM and AO); special populations: seniors with IBD (GN, HS and LT); and extra-intestinal disease (CB and GK). A complete overview of the objectives, working committees and methodology of creating the report can be found in the online supplemental file, Technical Document.

**THE IMPACT OF IBD IN CANADA: REPORT SUMMARY**

**IBD in Canada**

Canada has among the highest reported prevalence (total number of afflicted people) and incidence (number of new cases per year) rates of IBD in the world (9–11). In 2018, approximately 270,000 Canadians are living with IBD: 135,000 individuals with Crohn’s disease, 120,000 with ulcerative colitis and 15,000 with IBD type unclassified (IBD-U) (12). Currently, seven out of every 1000 Canadians have IBD (12). By 2030, the number of people living with IBD is expected to rise to over 400,000, or approximately 1% of the population (12).

The highest reported incidence of IBD is in Nova Scotia at 54.6 new cases per 100,000 people per year (13), and the lowest is in British Columbia at 18.7 per 100,000 people per year (14). The incidence of IBD in Alberta, Manitoba, Ontario, Quebec and Saskatchewan are similar, ranging from 21.6 to 28.3 per 100,000 people per year (14–17).

IBD can be diagnosed at any age but has a typical age of onset in adolescence or early adulthood (18). Because of this, IBD often affects Canadians during critical years of schooling and career growth (18). IBD in Canada impacts the lives of all ethnicities and religions (19). However, the rate of new diagnoses of IBD is higher among those of Ashkenazi Jewish and South Asian descent and lower among those of East Asian descent (19, 20).

People with Crohn’s disease face a significantly elevated risk of premature death compared with the general population (21), and people with IBD face a higher risk of bowel cancer (22). The risk of several extra-intestinal diseases, such as osteoporosis, liver disease, venous thromboembolism and cardiovascular disease, is high in patients with IBD (23, 24). Moreover, many people with IBD are codiagnosed with one or more immune-mediated inflammatory diseases, such as iritis, ankylosing spondylitis or primary sclerosing cholangitis (23, 24). IBD is more than twice as common as multiple sclerosis or Parkinson’s disease, about as common as Type 1 diabetes or epilepsy and slightly less common than rheumatoid arthritis and psoriasis (25–27). Consequently, with the exponentially rising number of Canadians with IBD, health policy makers will need to prepare our health care system for the rising burden of IBD (11).
Rising Rates of IBD in Canadian Children
There are over 7000 children under the age of 18 years old living in Canada with IBD, and the prevalence of IBD in children has risen more than 50% in the last 15 years (16, 28, 29). The rate of new diagnoses of IBD in children is rising rapidly; in particular, the number of newly diagnosed children under 5 years old rose by 7.2% per year between 1999 and 2008, and this rate is expected to continue rising due to improved recognition, greater availability of pediatric IBD specialists and, potentially, changes to the environment (16, 28, 29). Children with IBD have different complications of IBD, respond differently to treatments and are at greater risk for some medication side effects compared with adults (30–32). Children with IBD also incur greater costs of treatment than their adult counterparts due to more severe disease course and more frequent health visits (33, 34). Moreover, the effects of having a chronic disease can affect the entire family and other caregivers (35, 36).

Seniors with IBD: the Fastest Growing Group
The Canadian health care system must be prepared for a rising number of senior patients living with IBD (16). Seniors with IBD are the fastest growing group of people living with IBD, and the Canadian health care system must be prepared to face this challenge (16). The rising prevalence of IBD in seniors is the result of new diagnoses made in this population and the advancing age of previously diagnosed patients with IBD who carry the disease with them for the rest of their lives (37, 38). Seniors with IBD face complications of longer disease duration and the challenge of caring for age-related comorbid conditions such as diabetes and cardiovascular disease (37, 38). Therapeutic interventions need to balance the goal of clinical remission against the increased susceptibility to complications of the medications faced by seniors (39–41). Accordingly, IBD health care providers must be prepared to work in multidisciplinary teams with other specialists to optimize IBD management in the context of the unique challenges faced by seniors with IBD (38).

Quality of Life for People with IBD
IBD often affects individuals in adolescence and early adulthood, a time when they are pursuing employment, building their family and reaching key milestones (7, 42). The impact of IBD on quality of life (QOL) is multifaceted, from direct physical impairment due to symptoms like diarrhea and abdominal pain to financial burdens associated with health care encounters, in addition to psychological distress stemming from factors such as symptoms, distorted perception of body image, fear of sexual inadequacy, social isolation, fear of dependency, concern about not reaching one’s full potential and fear of stigmatization (8, 43, 44). Even patients in remission frequently experience psychological distress (42–45). IBD affects QOL of the family unit as well because stress on immediate family members is commonly experienced (35, 36). Mitigating the burden of QOL faced by people with IBD requires transdisciplinary care, including mental health care providers who can work with patients to develop adaptive coping mechanisms that help manage illness perceptions and reduce psychological distress (46, 47).

Challenges Facing Patients with IBD
In addition to the tremendous impact that IBD has on QOL, people living with IBD face a myriad of other challenges. These include prolonged symptoms due to late or inappropriate diagnosis, social stigma of having a chronic disease that affects toileting habits, difficulty with excursions due to limited or uncertain access to bathroom facilities, affordability of medications, diminished employment prospects, limited community-based supports, and inequitable access to health care services and specialists (48–50). Reducing these inequities should be a priority for physicians and policy makers to improve QOL and productivity of IBD patients in society. Of particular note is the issue of equal access to care across Canada. Patients cared for by gastroenterologists have better outcomes, including lower risk of surgery and hospitalization (49, 51). Canadians with IBD who live in rural and underserviced areas are less likely to be cared for by gastroenterologists (52). Improving timely access to gastroenterologist care may reduce the risks of requiring surgery and emergency care among patients with IBD (49, 51, 52). Reducing variation in care for patients with IBD should focus on timely diagnosis of IBD and regular follow-up of patients with IBD with gastroenterologists.

Economic Costs of IBD
The health economic impact of IBD in Canada is high. Economic costs for IBD are conservatively estimated at $2.6 billion CAD in Canada in 2018. Direct medical costs are approximately $1.28 billion CAD, dominated by costs of prescription drugs and hospitalizations (53, 54). There is a steady shift towards pharmaceuticals being the predominant driver of direct costs in IBD patients due to the introduction and widespread use of effective, yet expensive, biological therapies (55–57). The introduction and gradual penetration of biosimilar agents at a lower price point than their originator counterparts could mitigate escalating costs of IBD care in coming years. However, the increasing use of biologics overall alongside a growing IBD prevalence may still dominate the cost impact for years to come (11).

The high direct cost of treating IBD is compounded by the high indirect costs of illness, including loss of economic productivity of patients and their caregivers and out-of-pocket expenses (58). The indirect health-related costs attributable to IBD are estimated
to be $1.29 billion CAD annually in 2018. Indirect costs are dominated by productivity losses, particularly premature retirement ($629 million CAD in permanent lost wages accrued annually). Other factors include medical absenteeism ($88 million CAD annually), premature death ($34 million CAD annually) and out-of-pocket expenses ($541 million CAD annually) (58–60). Importantly, other factors that may contribute substantially to indirect costs, such as costs related to presenteeism, reduced professional development and lost caregiver productivity, are not accounted for in the overall estimate due to limited data and should be a focus of future studies in IBD patients (58–60).

RECOMMENDATIONS

Adults and children living with IBD face a number of critical challenges. The personal and fiscal burden that IBD places on individuals, the health care system and society is significant and will become more problematic as the number of patients with IBD increases. We provide the following recommendations to address the burden of IBD in Canada:

• Increase funding for research into preventing and treating IBD and addressing the physical, psychological, and social issues caused by IBD
• Introduce greater public and private investment in IBD research and commercialization strategies so as to expedite translation of academic-based research discoveries into clinical applications in humans
• Improve recognition and funding for research into special populations of people with IBD, including children, seniors and pregnant women
• Recognize IBD is a national health priority and increase resource allocation for chronic care models that reflect the episodic nature of IBD to optimize health care delivery to this population; this is the responsibility of the federal government.
• Enact a national public health campaign and patient education programs to raise awareness and knowledge among the general public and health care professionals to facilitate earlier diagnosis and reduce social stigma associated with IBD; leadership for such a campaign could come from Crohn’s and Colitis Canada.
• Introduce public and private sector programs (including laws) that foster open access to washroom facilities for people with IBD or incontinence
• Ensure timely and appropriate access to gastrointestinal specialists, allied health care professionals, endoscopy and radiology services for those who are waiting for diagnosis or treatment of IBD, particularly in rural and underserviced areas
• Enhance and harmonize public and private drug plans so that patients with IBD—no matter where they live in Canada, their age or their socioeconomic status—have equal and better access to medically prescribed pharmaceuticals that improve a patient’s health and quality of life
• Improve drug review processes reflecting the latest research and best practices so that therapies of benefit to people with IBD are approved and available more quickly
• Introduce appropriate income security measures and employee assistance programs that offer support for chronic disease patients

To improve the current IBD care and awareness in Canada, Crohn’s and Colitis Canada must advocate to government, media, the general public and other key stakeholders to move these recommendations forward.

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