

## Supplement Article

# The Impact of Inflammatory Bowel Disease in Canada 2018: Quality of Life

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## Abstract

Inflammatory bowel disease (IBD) has a substantial impact on quality of life. It causes considerable personal, emotional and social burdens. The impact of IBD on quality of life cannot readily be quantified as a cost; however, the impact places a significant burden on the patient and caregivers. Numerous studies have shown that health-related quality of life is impaired in patients living with IBD as compared with the general population. While disease activity and severity is an important driver of physical and mental health-related quality of life, patients may experience psychological distress even during clinical remission. Reduced quality of life can impact persons living with IBD as they pursue employment, family planning and personal milestones. Further, the impact of IBD extends to the patient influencing the quality of lives of those around them, including their caregivers. Improving quality of life requires a multidisciplinary approach that includes screening for and managing psychological distress. Adaptive coping mechanisms help manage illness perceptions and reduce psychosocial distress.

## Highlights

1. Health-related quality of life (HRQOL) is an important measure of the global impact of IBD on a person's physical, mental and emotional well-being.
2. Persons living with IBD have significantly lower HRQOL compared with that of the general population.
3. Inflammatory bowel disease often affects individuals as they pursue employment, family building and personal milestones.
4. Inflammatory bowel disease affects the quality of life (QOL) of those afflicted and their caregivers.
5. Access to multidisciplinary, collaborative, chronic disease models of care improves the HRQOL of people living with IBD.

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### Key Summary Points

1. Inflammatory bowel disease impairs HRQOL by inhibiting need fulfillment (i.e., self-esteem, relationships, nutrition, hygiene and security) and causing psychological distress.
2. Inflammatory bowel disease impairs interpersonal relationships, life activities, social participation and mental well-being.
3. Patient symptoms like diarrhea and abdominal pain reduce HRQOL.
4. While disease severity is an important driver of physical and mental HRQOL, patients experience psychological distress even during clinical remission.
5. Psychological distress impairs work productivity and disrupts social activities and relationships.
6. Patients with IBD experience emotional distress relating to factors such as loss of bowel control, impairment of body image, fear of sexual inadequacy, social isolation, fear of dependency, concern about not reaching one's full potential and fear of stigmatization.
7. Families with children with IBD have impaired QOL as a collective—for example, parental stress from medical factors and child's perceived stress.
8. Patients' perception of their illness affects their ability to adjust to a diagnosis of IBD. Adaptive coping mechanisms help manage illness perceptions and reduce psychosocial distress.
9. Biologics are associated with improvement in long-term HRQOL in people with IBD.
10. Patients with IBD should have access to multidisciplinary care, including mental health practitioners, to screen for and manage psychological distress.

### Gaps in Knowledge and Future Directions

1. Patients with IBD experience emotional distress that reduces HRQOL. Clinical tools are necessary to identify the key factors causing psychological distress in patients with IBD.
2. HRQOL is reduced in individuals with IBD and their families. Studies should evaluate the cumulative burden of IBD on HRQOL in patients with IBD and their caregivers.
3. Patient self-perception of their IBD influences their HRQOL. Clinical studies of interventions that improve adaptive coping are needed to reduce psychosocial distress.
4. Multidisciplinary care including a psychologist to screen for and manage psychosocial risk and psychological distress should be evaluated in IBD clinics.

**Keywords:** *Inflammatory bowel disease; Crohn's disease; Ulcerative colitis; Quality of life; Epidemiology*

Quality of life (QOL) is a broad, multidimensional concept that usually includes subjective evaluations of both positive and negative aspects of life (1, 2). The Centre for Disease Control has defined QOL as “an individual's or group's perceived physical and mental health over time.” (1) The concept of health-related quality of life (HRQOL) and its determinants has evolved since the 1980s to encompass aspects of overall QOL that have been shown to affect either physical or mental health (1, 3, 4). Health-related quality of life questions have become an important component of public health surveillance and are considered valid future indicators of unmet needs and intervention outcomes. Self-assessed health status is a more powerful indicator of mortality and morbidity than many objective measures of health (5, 6).

Health-related quality of life is impaired at some point in every patient with IBD, and many live chronically with

impaired HRQOL. Inflammatory bowel disease affects young individuals at a time in their lives when they are most likely to be pursuing major employment, family planning and personal milestones of critical importance. The pursuit of such critical milestones is often impeded by the unrelenting and debilitating symptoms and the psychological distress associated with IBD (7–10). Measuring and evaluating the disability associated with IBD and the impact of IBD on a person's quality of life is paramount to understanding the often hidden burden of this disease for persons living with IBD and for society as a whole. This section of the report will characterize the impact of quality of life on patients with IBD. A complete overview of the objectives, working committees and methodology of creating the report can be found in the online supplemental file, Technical Document.

## WHAT INFLUENCES QUALITY OF LIFE IN PEOPLE LIVING WITH IBD?

### Compounding Factors: Disease Activity and Psychological Distress

On balance, data from most population-based studies suggest that persons living with IBD have significantly lower HRQOL when compared with that of the general population; this is particularly true for those with more severe disease activity (11–17). Disease severity remains the most significant predictor of physical and mental HRQOL (18). Compared with individuals in the general population, the QOL domains most impacted in patients with IBD were general health, mental health and social functioning. These findings also hold true for children with IBD. Youth with IBD have lower HRQOL compared with their healthy peers (19–22) and higher levels of impaired school-related HRQOL than healthy or chronically ill youth (22).

A study in which conversational interviews of persons living with Crohn's disease were conducted demonstrated that Crohn's disease had a major impact on need fulfillment (i.e., self-esteem, relationships, nutrition, hygiene and security) (23). Additionally, disease activity and psychological distress have been shown repeatedly to significantly impair the QOL in both children and adults living with IBD (24–26). Patients who have had surgery also experience impaired QOL (27). Patients with IBD experience significant psychological distress and have significant concerns related to surgery, degree of energy and body image issues (especially concerning the need for an ostomy bag) (28). Pain is a commonly reported symptom among adult patients with IBD, which further leads to impaired QOL.

In addition to disease severity and psychological distress, family-level factors can also affect HRQOL (29, 30). In a study by Gray et al., parental stress levels (both that related to medical factors and perceived stress) were shown to mediate the relationship between disease severity and HRQOL in adolescents with IBD (29). Higher levels of parental distress were associated with reduced HRQOL among adolescents with IBD (29). Knez et al. reported that parents of children with IBD report a significantly lower psychological health compared with parents of other children and significantly lower physical health compared with parents of healthy children (31).

Even during periods of disease remission, patients experience psychological distress that can impact their QOL (32, 33). How one perceives one's illness has been shown to have a major influence on the ability of an individual to adjust to a diagnosis of IBD. Adaptive coping mechanisms are critical to manage illness perceptions effectively and to reduce psychosocial distress (34). High levels of psychological distress have been demonstrated to be associated with increased risk of disease flares (10, 35, 36). The ability to work and participate in social activities is impaired by high levels of psychological distress and leads to modifications in lifestyle and disruptions in social relationships and family life (37).

Several concerns highly specific to IBD contribute to IBD-related emotional distress. These include concerns of loss of bowel control, fatigue, impairment of body image, fear of sexual inadequacy, social isolation, fear of dependency, concern about not reaching one's full potential, fear of stigmatization and feeling unclean (35, 36).

### Mitigating Factors: Clinical Remission and Value of Psychological Support

Although there is a lack of evidence that psychological interventions alter the course of IBD itself, they have been shown to improve HRQOL (38–40). Therefore, people living with IBD require access to providers with the ability to screen for and manage psychological distress as part of a multidisciplinary care approach. The Patient-Reported Outcomes Measurement Information System (PROMIS) is newly validated and is a reliable tool for evaluating patient-reported QOL. In addition, there are PROMIS tools that can be used to evaluate functional, gastrointestinal and psychiatric symptom severity in ambulatory adult patients with IBD. PROMIS measures may prove to be useful tools to apply in the ambulatory setting on a broader scale for follow-up of HRQOL (41).

Several avenues can be used to mitigate the negative impact of IBD on HRQOL. The implementation of effective disease therapies to decrease disease severity through the induction and maintenance of long-term clinical remission is one area of critical importance (42). Before the availability of biologic therapies for the treatment of IBD, the use of steroids, 5-ASA and immune modulatory therapies were not associated with long-term improvements in HRQOL. However, biologic therapies may lead to long-term improvements in HRQOL (28, 43–45). A comprehensive review by Vogelaar et al. revealed that long-term, sustained improvements in HRQOL are achievable in patients receiving therapy with infliximab, certolizumab, adalimumab and natalizumab (43). GEMINI I and II show the positive impact of vedolizumab on HRQOL (46).

Screening for psychological distress and the provision of patient-centred management approaches to help mitigate this distress is a critical—but often overlooked—foundational principle of the multidisciplinary care that should be provided through collaborative care programs.

Uncertainty is another factor associated with reduced HRQOL (47). Health information gathering through the internet by patients with Crohn's disease has been associated with reduced certainty (47). Therefore, the provision of well-designed, evidence-supported, patient-oriented, educational tools could also help reduce the level of uncertainty and help improve HRQOL. Highly educated patients who are actively engaged in their healthcare are more likely to be empowered and to achieve improvements in HRQOL.

## QUALITY OF LIFE AND PEDIATRIC IBD

### Unique Issues to Consider in or with Respect to Measuring/Assessing QOL in Children with IBD

In contrast to adults, assessing QOL in pediatric patients with IBD requires one to address two unique issues: whether to use a proxy, or question the children directly (48, 49) and how to accommodate varying developmental levels and ages (50, 51).

A proxy reporter of the child's QOL is required while a child's age or developmental ability limits their comprehension. The proxy reporter of the child's QOL is most often a parent/caregiver. In some cases, another individual such as a teacher or physician, with sufficient knowledge of the child, may act as the proxy (49). However, using a proxy presents additional challenges. Evidence indicates that proxies tend to have a low to modest agreement with the child's reported QOL self-assessment (52). A greater degree of agreement is noted the more objective the dimension of QOL being assessed. Parents and teachers agree fairly well in reporting on child functioning but

markedly less well for recent functional status and certain types of subjective feelings in regard to illness, information needs, emotional states and family functioning (53).

The changes seen in a child's expressive and receptive language across the wide developmental spectrum seen for the pediatric age group impacts the quality of the self-report (50). As well, a child's ability to respond to questions based upon experiences during a specific time period will be dependent on their time perception and memory, both of which develop over time – and the ability of a young child and adolescent to carry out these tasks would differ (Table 1) (49).

### Pediatric IBD QOL Comparisons

Ryan et al. report on incorporating HRQOL screening into clinical practice and its clinical utility in predicting disease outcome and healthcare utilization (54). This study demonstrates that youth who report lower HRQOL at baseline, on average, have increased healthcare system utilization as measured by

**Table 1.** Factors that influence QOL in people living with IBD

	Impact on QOL		Mechanism of influence on QOL
	Children	Adults	
IBD disease activity (18, 19–22, 24–26)	Negative	Negative	<ul style="list-style-type: none"> <li>• Self-esteem</li> <li>• Relationships</li> <li>• Hygiene</li> <li>• Security</li> <li>• Depressive symptoms</li> <li>• Social isolation</li> <li>• Psychological distress</li> </ul>
Psychological distress (25, 26, 32, 33)	Negative	Negative	<ul style="list-style-type: none"> <li>• Reduced energy</li> <li>• Impaired body image</li> <li>• Maladaptive coping mechanisms</li> <li>• Social isolation</li> </ul>
Psychological interventions (39, 40)	Positive	Positive	<ul style="list-style-type: none"> <li>• Reduction of exacerbating factors related to increased disease-related psychological distress</li> </ul>
Surgery (27)	Negative	Negative	<ul style="list-style-type: none"> <li>• Fear of complications</li> <li>• Need for an ostomy</li> <li>• Body image</li> <li>• More severe form of disease</li> </ul>
Pain (28)	Negative	Negative	<ul style="list-style-type: none"> <li>• Disability</li> <li>• Depressive symptoms</li> <li>• Disease-related psychological distress</li> </ul>
Parental stress (29, 30)	Negative	Unknown	<ul style="list-style-type: none"> <li>• Perceived difficulty of medical stressors</li> </ul>
Effective medical therapy (28, 42–46)	Positive	Positive	<ul style="list-style-type: none"> <li>• Induction of long-term remission</li> </ul>
Health information gathering from internet (47)	Negative	Negative	<ul style="list-style-type: none"> <li>• Reduced certainty</li> </ul>
Poor sleep quality (61)	Negative	Negative	<ul style="list-style-type: none"> <li>• Fatigue</li> <li>• Daytime dysfunction</li> </ul>



IBD-related hospital admissions, emergency department visits, use of psychological services, telephone calls to clinicians, GI clinic visits and referral to pain management.

Early work has also been done comparing HRQOL of pediatric IBD patients with healthy peers (55). Not surprisingly, Haapamaki et al. demonstrate that children ages 7–19 with IBD have significantly lower HRQOL scores compared with age-standardized healthy peers. Kunz et al. compared HRQOL assessments of youth with IBD with published group data of chronically ill, acutely ill and healthy comparison groups (22). They showed that youth with IBD have higher physical and social functioning than the chronically ill group, lower psychosocial functioning than the healthy comparison group, and lower school functioning than all published comparison groups. Additional studies are needed to ascertain whether these findings are consistent across pediatric IBD patients, those with other chronic illnesses and healthy peers. As we gain improved understanding of the relationships between the various factors which contribute to HRQOL, we will be better positioned to design interventions that may address the modifiable factors, and evaluate whether this can result in sustained improvements in HRQOL for these youth with IBD.

## DISABILITY AND IBD

Disability can be defined as chronic limitations that hinder the ability to engage in usual daily activities and is an objective way of understanding the impact of IBD in someone's day-to-day life (56, 57). Disability is a relatively new area of study in IBD. The World Health Organization developed international standards in the assessment of disability using the International Classification of Functioning, Disability and Health. These tools have been used by researchers to develop generic and disease-specific instruments to evaluate disability in IBD. Ability to work was the most common IBD-related metric for disability. But this metric alone is not sufficient, given it does not capture all the important aspects of the burden of this condition. Additionally, with a relapsing/remitting condition like IBD, disability may be temporary and difficult to address (57).

Although disability studies in IBD have demonstrated increased rates of unemployment, sick leave and disability pension among IBD patients, most patients maintain their ability to work for many years following the diagnosis of IBD. Patients with IBD have impaired productivity (presenteeism) and loss of working hours (absenteeism) compared with healthy controls, with resultant economic losses for both the individual and society.

The greatest disability restrictions to QOL are described in the domains of interpersonal relationships, life activities, social participation and mental well-being (57, 58), although there

has been some discrepancy in the degree of disability between populations. These discrepancies may be related, in part, to differences between populations and cultures, as well as tools and means of assessing disability. There has been a consistent finding, however, of higher levels of disability in Crohn's disease patients compared with ulcerative colitis patients, particularly in the area of interpersonal relationships. Most patients impacted in the domain of interpersonal relationships have experienced limitations in making new friends, maintaining friendships and enjoying their sex life (57). Other areas impacted to a lesser degree include education, career pursuits, family planning and the financial burden of IBD (59).

The stigma associated with IBD sensitizes the communication with employers and schools. How best to communicate with employers and schools regarding IBD is a voiced area of concern, which is underrepresented in the available disease-related information accessible to IBD patients. In a European study (60), 60% of IBD patients reported feeling stressed by thinking of taking a sick leave from work due to IBD, and almost a quarter of patients had experienced unfair comments about their performance at work from colleagues or superiors. One way to reduce this burden is to facilitate open dialogue and increased awareness and to build a better understanding among the general population and employers of the impact of IBD on their colleagues and employees (58).

## CROHN'S AND COLITIS CANADA ADDRESSES QOL OF PATIENTS WITH IBD

Health charities can play an important role in filling gaps in the health system by supporting patients to live a better quality of life through both program and technological interventions. Crohn's and Colitis Canada supports research and also offers programs to support patients to have a better QOL. Regular educational events, in-person or through webinars, and social media are offered by Crohn's and Colitis Canada. In addition, the 46 chapters across Canada hold regular meetings and educational events. Patient support is available through the online Gutsy Peer Support program that matches patients to aid their discussions of disease management and quality of life. Through feedback from patients, Crohn's and Colitis Canada launched the GoHere program—a smartphone app that geo-locates businesses that provide IBD patients access to washrooms.

New technologies offer additional forms of support, as indicated by the following example: Through the Crohn's and Colitis Canada-funded Promoting Access and Care Through Centres of Excellence (PACE) research program, clinician-scientists are pilot testing a digital application with which patients can communicate their health status to their healthcare providers on a regular basis with the goals of minimizing wait times and aiding timely access to care.

## CONCLUSION

Inflammatory bowel disease often begins in young individuals at a time when they are pursuing education and employment, building their family and achieving key life milestones. Inflammatory bowel disease harshly influences HRQOL and introduces disability that can impair daily activities, thus affecting interpersonal relationships, life activities, social participation and mental well-being. The impact of IBD on HRQOL is multifaceted, from the direct physical impairment from symptoms like diarrhea and abdominal pain to psychological distress. Disease severity worsens physical and mental HRQOL. However, even in clinical remission, patients experience psychological distress. Psychological distress stems 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.

Health-related quality of life is uniquely impacted in children and adolescents with IBD. Moreover, the entire family can suffer collectively from reduced HRQOL because parental stress is commonly experienced. Consequently, the impact of IBD on HRQOL is an important burden for persons living with IBD and for society as a whole. Fortunately, strategies are available to mitigate the negative HRQOL that many patients with IBD experience. Physical determinants of HRQOL can be addressed with appropriate medical and surgical management. Psychological distress is addressed through multidisciplinary care including a psychologist who can work with patients to develop adaptive coping mechanisms that help manage illness perceptions and reduce psychosocial distress.

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