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Patient-ly Waiting: A Review of Patient-Centered Access to Inflammatory Bowel Disease Care in Canada

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Abstract

Canada has one of the highest prevalence estimates of inflammatory bowel disease (IBD) in the world. Like other chronic illnesses, access to specialist care is required for disease management. Traditionally, access to care is evaluated through wait times (actual access); however, new patient-oriented definitions of access (perceived access) highlight other equally important facets of access to care (e.g., appropriateness). Aim: How does access to gastroenterology speciality care influence disease-related outcomes for IBD patients in Canada? A comprehensive literature review was undertaken. Cochrane, PubMed and CINHAL databases were searched for peer-reviewed English language articles published between 2006 and 2016. Inclusion/exclusion criteria focussed on access to IBD care in Canada. Included articles were classified using Levesque et al.'s patient-centered access framework (e.g., affordability, accessibility, appropriateness, acceptability, availability and accommodation). Eight articles were found, including six which addressed patient-centered access. Most of the articles addressed issues of availability (e.g., wait times), appropriateness and affordability. Only one article addressed approachability and acceptability of IBD care. All articles emphasized a need for greater patient-centered measures (e.g., multidisciplinary clinics) with a goal to improve patient access and, ultimately, patient outcomes. Understanding patient-centered access to IBD care is important for managing IBD and improving patient outcomes. Literature examining access to gastroenterology services is limited. Increased investment in patient-oriented research should be made to better understand the relationship between access to specialist care and patient outcomes.

Keywords: *health services accessibility; inflammatory bowel diseases; patient-centered care.*

Disease etiology and epidemiology

Inflammatory Bowel Disease (IBD) is a chronic disease with lifelong debilitating effects on patients' and their family's physical, emotional and financial well-being. IBD patients can experience psychosocial and interpersonal concerns that cause emotional distress and impact the effectiveness of therapeutic treatments and health outcomes. The societal burden of IBD, including economic loss due to missed work and lost productivity, has been shown to be a significant cost to Canadians (1). Inflammatory bowel disease, including both Crohn's Disease (CD) and Ulcerative Colitis (UC), typically manifests itself in the second and third decades of life, but can also occur later in life (1, 2). There is no cure for IBD, and therefore, management involves lifelong medical treatment and interaction with the health care system (1). IBD poses special challenges to young adults diagnosed with IBD as they strive

to achieve other important educational, employment and family-building milestones.

Inflammatory bowel disease is most prevalent among North Americans and Europeans. Canada is reported to have the highest prevalence rates of UC and CD in the world (3, 4). Data suggest that one in 150 Canadians live with IBD (4). Within Canada, the province of Nova Scotia has the highest prevalence and incidence rates of IBD. Nova Scotia's age-adjusted incidence rate of CD is 20.2 cases per 100,000, compared to the national average of 13.4 cases per 100,000 (5). The Canadian age-adjusted incidence rate for UC is 19.5 cases for every 100,000 people, compared to 11.8 cases per 100,000 (5) . Each year, 10,200 Canadians are newly diagnosed with IBD (6). As with most chronic disease management, access to quality care is critical.

Access in healthcare redefined

"Access" to healthcare has previously been defined as "the fit between the individual and the healthcare system" (7). This definition has been reworked in recent years. Fortney et al. suggest that access should be defined as both 'actual access' and 'perceived access' (7). Actual access includes those "directly observable and objectively measurable dimensions of access," such as wait time between referral and consultation. Perceived access is defined as the "self-reported and subjective dimensions of access," such as patient knowledge of disease and options for care or the cultural appropriateness of care (7). Perceived access is more relevant from a patient perspective because it offers greater insight into the patient experience and allows decision makers to better understand factors relevant to access that are not always evident to a health care provider, administrator or policy maker. There also may be financial or geographic barriers to access, including access to out-of-pocket IBD medications, barriers caused by employment or education commitments, and the consequences of these barriers.

A recent framework of access presented by Levesque et al. defines access as "the opportunity or ease with which consumers or communities are able to use appropriate services in proportion to their needs" (8). Highlighting the complexity of access, Levesque et al. have proposed five factors central to achieving access (Figure 1). These factors are approachability; acceptability; availability and accommodation; affordability; and appropriateness.

Importance of access for patients with IBD

Studying access to care for IBD.

Studies that critically evaluate the impact that access to specialty care has on patients living with IBD are limited. The prioritization by funding agencies and governmental organizations, including the Canadian Institute of Health Research's Strategy for Patient Oriented Research (SPOR), of patient-oriented approaches highlights the importance of acknowledging

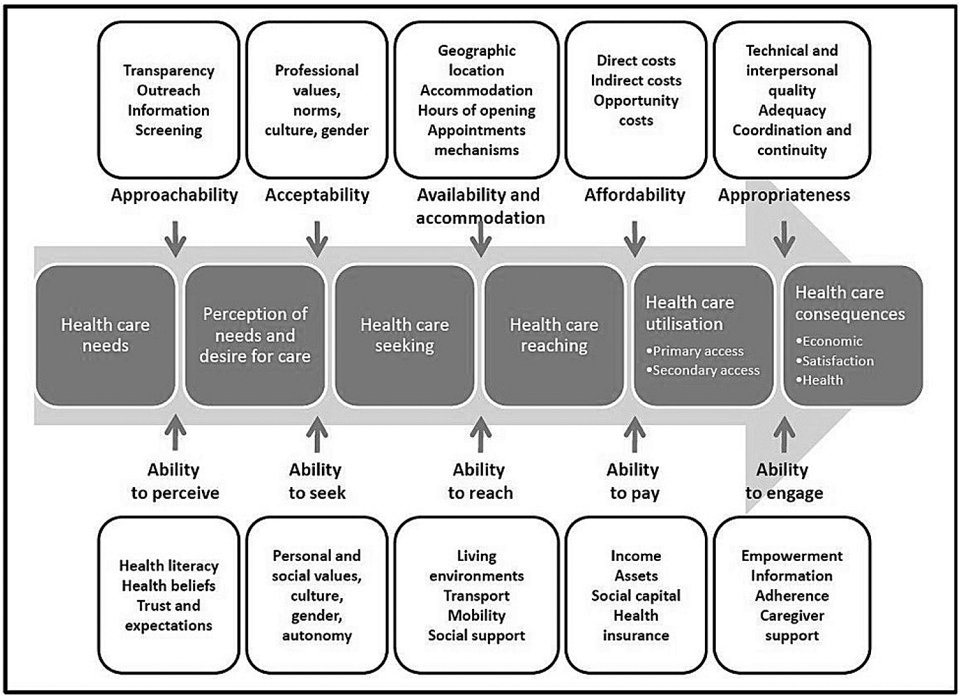

Figure 1. The Levesque et al. conceptual framework of patient-centered access (8). This framework examines the facets of perceived access (approachability, acceptability, availability and accommodation, affordability, and appropriateness) and their factors, which give greater insight into how patients experience access to health care services. The figure also presents the patient abilities that should be developed in order to improve access to services (e.g., ability to perceive). The facets of access and patient abilities are both used to develop how society understands the health care system. Note: Reproduced with permission from "Patient-centered access to health care: conceptualizing access at the interface of health systems and populations." Copyright ©2013 by Levesque et al; licensee BioMed Central Ltd.

the complexity of access to care and understanding the concepts of actual and perceived access, as demonstrated through the Levesque framework (9).

Our objective was to review the literature to determine whether perceived or actual access to specialty care influences disease-related (e.g., hospitalizations, surgeries) and patient-oriented (e.g., quality of life, patient satisfaction, knowledge, self-management) outcomes in IBD patients in Canada. Additional literature concerning advances in access to IBD care from a global perspective was also included, in order to inform potential advances in the Canadian context.

PATIENT-CENTERED ACCESS TO IBD CARE IN THE CANADIAN CONTEXT

A systematic search of multiple databases resulted in eight studies related to access to IBD care in Canada: two randomized control trials, three cohort studies, and three reviews. They are summarized in Table 1.

From these included studies, we can begin to examine areas of IBD care which are receiving attention and those where access needs to be improved. What follows is a summary of the identified literature viewed through the theoretical lens of Levesque's five a's of access.

Approachability of IBD care

Approachability is described as the patient's ability to identify services that exist and a patient's knowledge of their own health and IBD knowledge (8). Only the review by Bray et al. acknowledges the need for greater development of patient knowledge of IBD health care management (11). Because most gastroenterology (GI) services in Canada are provincially funded and typically accessed by referral, the patient must have knowledge about the clinic and ask to be referred, or their family doctor must appropriately refer their patient for further consultation. Approximately 15% of Canadians do not have access to a family doctor (18). Therefore, the referral-based nature of these clinics can make accessing services difficult. The patient may never consult with an IBD specialist if they lack a primary care physician or if their family doctor does not think or *know* it is necessary to make a referral. Alternatively, patients may rely on ER departments or walk-in clinics to receive a referral, placing additional burden on these services. Patients must develop their own knowledge of GI illnesses and self-advocate.

Acceptability of IBD care

Acceptability is defined by the sociocultural aspects used to measure whether the service being offered is acceptable for the patient (8). Bray et al. call for a greater understanding of IBD among all healthcare professionals and a move towards interdisciplinary care, particularly for children (11). Despite the varied demographic of IBD patients, there are no defined alternate IBD care options for those who identify as needing accommodation based on age, gender, disability or race. The options that are available are non-specific to IBD (i.e., female-identifying patients requesting a female physician). Due to the limited resourcing of the Canadian healthcare system, it is challenging to provide alternative options that address the unique needs of patients who identify with a marginalized or vulnerable patient sub-group. (e.g., transgender, indigenous, pediatric transition, pregnant patients). It is assumed that minority or vulnerable populations experience additional barriers to accessing care, including increased financial burden and cultural sensitivity of treatment (e.g., use of steroids or narcotics); however, no published research focusing on these populations was found during the review. Although there are some programs in place for pediatric transition populations, this remains a challenge in terms of initial access and re-accessing the healthcare system when necessary.

Availability & accommodation of IBD care (actual access)

Availability and accommodation focuses on the physical and temporal accessibility of the services (8). Three of the identified studies focused on availability and accommodation through temporal accessibility (e.g., wait times) or health care resource utilization (10, 13, 15).

Benchimol et al. evaluated the influence of socioeconomic status on healthcare outcome in 2230 children diagnosed with IBD using population-based health administrative data (HAD). Compared to high-income neighbourhoods, children from low-income neighbourhoods were more likely to be hospitalized at least once (hazard ratio, 1.17; 95% CI, 1.05 to 1.30) or to visit the emergency department (hazard ratio, 1.21; 95% CI, 1.09 to 1.35), and had more IBD-related physician visits (OR, 3.73; 95% CI, 1.05 to 13.27). Children from low-income neighbourhoods with CD were more likely to undergo intra-abdominal surgery within three years of diagnosis (OR, 1.22; 95% CI, 1.01 to 1.49), especially when diagnosed after 2000 (OR, 1.79; 95% CI, 1.27 to 2.53) (10).

Nguyen et al. conducted a population-based study using HAD from Ontario to evaluate healthcare resource utilization amongst patients with late-onset IBD (diagnosis of disease at ≥ 65 years). Patients with late-onset disease were less likely to have an IBD-specific gastroenterology visit within the first year, less likely to receive continuous gastroenterology care, and less likely than younger IBD patients to require an emergency room visit or be hospitalized within the first year after diagnosis (15).

In 2006, the Canadian Association of Gastroenterology (CAG) convened a panel of experts to determine acceptable wait times for various GI disease states. It was agreed that for patients with symptoms suggestive of active IBD, wait times should not exceed two weeks. Leddin et al. published the results of a CAG-initiated practice audit survey (the PAGE program) which estimated the

Table 1. Overview of Literature Included in Review

Author (year)	Study Design	Access Lens	Summary
Benchimol et al. (2011)	Population-based prospective cohort	Availability & Accommodation	Low socioeconomic status (SES) is associated with increased health care utilization among pediatric IBD patients in Ontario and increased risk of surgery among pediatric Crohn's patients in Ontario (10).
Bray et al. (2016)	Commentary	Acceptability, Approachability, Appropriateness	Patients at the 2015 Crohn's and Colitis Canada "Patient and Healthcare Professional Summit on the Burden of Disease in IBD" stressed the need for equitable access to care. The paper offers recommendations for public awareness, advocacy and research development (11).
Huang et al. (2014)	Systematic review/ Meta-analysis of randomized control trials	Appropriateness, Availability & Accommodation	Distance management for IBD patients significantly decreases the number of clinic visits without having a significant effect on relapse rates or hospitalization rates, meaning that patient knowledge may be more relevant than distance (12).
Leddin et al. (2008)	Cohort study and Consensus meeting	Availability & Accommodation	The actual wait times between first referral and first consultation for seven indicators of digestive disease were greater than CAG consensus targets. Several interventions should be implemented to improve access to digestive care (13).
Mikocka-Walus et al. (2014)	Cross-sectional mixed method online survey	Appropriateness, Affordability, Availability & Accomodation	Based on survey findings of IBD health professionals, the ideal IBD service was found to include full integration of health professionals, a significant role of nurses and other allied health professionals, offer specialist care, be free of cost and be accessible for IBD patients (14).
Nguyen et al. (2015)	Cross-sectional study	Availability & Accommodation	Late onset IBD patients (>65 years) were less likely to use IBD health care than young adults with IBD. Lower utilization could be due to disease-related factors or problems with access, meaning that the total effect on outcomes is unknown (15).
Rocchi et al. (2012)	Literature review	Affordability	In Canada, IBD has a high disease burden (direct and indirect costs) given its high prevalence and high per-patient costs. Quality of life is also low compared to healthy Canadians (16).
Rogala et al. (2008)	Longitudinal cohort study	Affordability	IBD patients experience increased difficulties with work quality and daily activities compared to non IBD patients. However, they experience similar levels of stress, while having "more tangible, affective [and] emotional support" (17).

mean wait times for patients with symptoms suggestive of IBD across Canada. These derived actual mean wait time estimates were then compared to acceptable wait times previously defined through the Delphi panel. The mean wait time for existing IBD patients was 101 days (versus the recommended 14 days) with a broad range of reported wait times ranging from 35 days (25th centile) to 209 days (75th centile) (13).

Affordability of IBD care

Affordability constitutes the financial and temporal resources needed to access a service (8). No literature was identified that evaluated financial accessibility for the patient, and very little work addresses the socioeconomic burdens of IBD in Canada. Bray et al. briefly addressed the need for affordable medications (11). Rocchi et al. conducted a literature review of Canadian

sources to better understand the IBD disease burden, including direct and indirect economic and social costs (e.g., missed work, direct patient expenses, private/public drug claims), among Canadian patients in 2012 (16). They concluded that there is a high burden of illness related to IBD and noted perceived access to care as one of the main challenges facing patients. Finally, using data derived from the Manitoba IBD Cohort Study, Rogala et al. noted the increased strain of work and school absenteeism on IBD patients in comparison to other community members in good health (17).

Appropriateness of IBD care

Appropriateness indicates the fit between the patient's needs and what the service offers. In order to measure appropriateness, the patient should have the ability to engage with the service (8). Huang et al. conducted a systematic review and meta-analysis of randomized control trials to measure the impact of distance management (e.g., telemedicine, web-based interventions) and follow-up care on adult IBD patients (12). They found a correlation between distance management and reduced hospitalization, whereas IBD patients who participated in distance management programs experienced fewer hospitalizations than IBD patients who relied on clinic visits for management. Distance management allowed for nurse practitioners to follow up with patients over the phone, reducing the overall burden on clinical programs and patients lost to follow up.

Bray et al. advocated for treatment adaptable to the individual patient, emphasizing the importance of appropriateness (11). For example, a collaborative clinic with a health psychologist may be offered to patients who are struggling with psychosocial aspects of their IBD diagnosis. Further, Mikocka-Walus et al. found that IBD professionals agreed that accessible integrated care was the ideal model of care, highlighting the tenet of appropriateness (14).

LESSONS FROM ABROAD: ADDRESSING ACCESS TO IBD CARE ON THE GLOBAL LEVEL

Literature on patient-centered access to IBD services has been growing in other areas of the world, including Australia, Europe and the United States. Most interestingly, these growing bodies of international literature address key gaps in Canadian literature, including cost-benefit analyses and analyses of racial health inequities. A search of Canadian literature showed no race-based analysis of access; however, in the United States, literature shows that Asian-Americans are more likely to be hospitalized for their Crohn's Disease, while African-Americans are more likely to use emergency services (19). Another article found discrepancies in access between races in the United States, with lower disease-related knowledge amongst racial minorities (20). Literature from the United States and Brazil also focus on socioeconomic factors relating to access, including work and school absenteeism, lost earnings and quality of life (21, 22). Again, there has yet to be a comprehensive national cost-benefit analysis done within Canada.

Literature from other nations highlighted the importance of having the patient perspective in the design of health services. In Scotland, a study incorporated the patient perspective in the co-design of IBD services, which highlighted the importance of having a system navigator, dedicated IBD nurses and better coordination of related services (e.g., psychiatry and dietetics) (23). A Swedish study involving a focus group of patients had similar findings. Patients with IBD suggested a restructuring of services in order to allow for shared decision making and improved communication (24). Australian and Dutch researchers focused on engaging patients with telemedicine and eHealth initiatives. In their respective studies, it was determined that patients were willing to utilize technology to self-manage their IBD because it was effective and allowed them to take control of their health in regions where they may otherwise have poor access to services (25, 26). The patient perspective was also central in the development of the 2014 Delphi Consensus Statement, which lays out indicators of quality in IBD care based on the input of IBD physicians, nurses and patients (27).

Where to go from here?

Access to healthcare has long been recognized as essential to improving patient outcomes (8). Quality of IBD care is important and integration of evidence-based medicine is a critical step toward improving health care delivery (19). The incorporation of collaborative health care delivery changes that facilitate the five a's of access is important for the management of all chronic diseases, including IBD (14, 28).

Most of the available literature on improving access to healthcare in Canada focuses on primary health care. Literature that does focus on specialist care emphasizes reduction of wait times, rather than addressing perceived access. Literature concerning access to IBD care is sparse compared to literature on other health concerns, like cancer and mental health, which are key priorities within Canada's current SPOR (9).

The current review identified a small number of articles that address actual access (e.g., service utilization), perceived access, and the impact of access, or lack thereof, on patients, families, the healthcare system and society at large. No Canadian literature was identified that explored the impact of models of IBD care access on these biopsychosocial and institutional dimensions. The clear gap identified in national access knowledge, coupled with limited IBD access–related research activity, is concerning and suggests that we are operating within a knowledge void. Canada also stands to learn a lot from the body of international literature—not only from their outcomes but from

their designs and approach to research. There is a pressing need to take a broader approach to understanding access in order to overcome barriers and to appropriately invest in facilitators of access for IBD patients. Understanding the health, social and financial burdens presented by inequitable care is essential in order to make future cost-effective, patient-oriented improvements in health care delivery.

There are still many unanswered questions concerning the impact of both actual and perceived access to IBD care on patient outcomes. There is little data on outcomes such as risk of surgery, quality of life and access to medications. Very little information is published in relation to chronic GI tract conditions and the impact of IBD specific wait times on outcomes. The Canadian Institute for Health Information found that longer wait times resulted in increased worry, pain, interference with daily life, and deterioration in overall health (29). Within gastroenterology, multiple benchmarks have been set by The Wait Time Alliance and the CAG (29, 30). The Wait Time Alliance states that by focusing on wait times, access to health care can be improved (31). However, the reduction of wait time alone is not enough to improve access to care. Model innovation that will facilitate health care access requires a greater depth of knowledge of system- and patient-related factors. Providing access to IBD care in rural and remote areas has proven to be one of the biggest challenges for health care systems. Most often, rural patients will have to travel to urban areas to receive care—regardless of urgency. Chronic diseases are more prevalent in rural populations, yet there are greater transport difficulties for this cohort of patients (32). Travel represents an extra financial and temporal cost and signifies additional stress for the patient (32).

Focusing solely on wait times, to the exclusion of all other access-related considerations, provides a monocular view of a complex phenomenon. Researching and understanding perceived access is increasingly recognized by medical literature as a key component in developing patient-centered care. Some suggested research foci include the financial burden of IBD out-of-pocket medications. Although some health insurance plans may cover introductory drugs like oral 5-aminosalicylates (5 ASAs), biologic drugs are usually not covered. Use of these new drugs can cost tens of thousands of dollars each year (33). Medications represent a huge financial burden for IBD patients, yet are crucial for disease management, and barriers to drug access are likely having an impact on disease-related outcomes (34). Research areas directly related to access to care could include travel and absenteeism. Health systems planning would benefit from an extensive patient-centered cost-benefit analysis, as the current financial figures available only represent the overall national burden.

While there is an emerging literature on the role of integrated collaborative healthcare models in the management of IBD (14, 35), accessibility, affordability and appropriateness of Canadian IBD care remains poorly understood. Patient-oriented research is critical to help reform how health services are implemented and delivered. In an era of rising IBD disease incidence and prevalence estimates, soaring healthcare costs, and increased pressure to do more with less, innovation in how we provide access to and deliver care for our patients is greatly needed. Patient-centered research related to access to care will provide contextual data that will facilitate evidence-based decisions by policy makers. This evidence will inform where, why and how services should be delivered. Moving forward, patients and the health care system alike would benefit from relevant research to improve patient-centered care and gain a better understanding of the impact of access on patients' experiences with the disease.

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