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Original Article

Patient Perspectives of IBD Care and Services: An Integral Part of a Pan-Canadian Quality Improvement Initiative

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Abstract

Background: As beneficiaries of health service improvement initiatives, patients should have their perspectives of and gaps in care elicited to inform and guide the development of quality indicators to assess health care services. The purpose of this study was to identify patient perspectives amenable for conversion into measurable inflammatory bowel disease (IBD) care quality indicators.

Methods: Crohn's and Colitis Canada's Promoting Access and Care through Centres of Excellence (PACE) program organized four patient focus groups in three Canadian provinces in 2016 to capture the perspective of patients on IBD care services. The RQDA package in R was used for transcript analysis, theme identification and for building a theme hierarchy based on the number of citations. The main themes were converted into patient-derived quality indicators.

Results: Several perceived unmet needs were elicited from participants that could be converted into measurable quality indicators. These unmet needs addressed the need for information, access to multidisciplinary services and specialized care, and access to psychological support. Patient unmet needs informed the selection of nine quality indicators that were included in the final list of PACE indicators to assess IBD care services across Canada.

Conclusions: Our study provides a detailed description of patient perspectives on IBD care services that were an integral part of the development of measurable indicators of the quality of care in the context of a universal health care system.

Keywords: *IBD; Patient perspective; Quality improvement*

Introduction

In North America and Europe, current practice patterns for key therapeutic decisions in inflammatory bowel disease (IBD) management vary among health care providers (1–4). Variations in health care access and delivery create significant gaps in and barriers to improving the quality of care for IBD patients. Mitigation of these barriers requires the development and implementation of innovative models to enhance care delivery nationally, in a standardized and monitored setting (2,5–7).

The Promoting Access and Care through Centres of Excellence (PACE) program was launched by the Crohn's and Colitis Canada in 2016. PACE is an innovative collaboration across a network of five leading IBD centres in Canada with the goal to improve patient outcomes, address current gaps through research and clinical care, and provide evidence to create changes in the public health care system. An important component of the PACE program was the development of quality indicators to standardize the assessment of quality improvement activities for IBD health care delivery. Involvement of patients was essential to determine relevant aspects considered for optimal IBD health care delivery (8). The findings of a systematic review on patient involvement in the development of quality indicators highlight the importance of both indirect (interviews, focus groups, etc.) and direct participation of patients and patient representatives in quality improvement initiatives (e.g., members in expert panel), in a similar manner that is becoming the standard in guideline development processes (9).

The aim of this article is to provide an in-depth description of the patient participation component in PACE, using focus groups to capture patients' perspective regarding IBD care services. Collection of qualitative data was instrumental to the development of the PACE quality indicators for IBD care (8). In writing this article, we followed the Consolidated Criteria for Reporting Qualitative Research (COREQ) (10).

METHODS

Rationale

As beneficiaries of health service improvement initiatives, patients should have their perspectives of care and gaps in care elicited and used to inform and guide the development of quality indicators to assess health care services.

Context—Site Locations

To account for potential variability in patient experience across Canada, four focus groups were organized in the summer of 2016 in three provinces: Quebec, Ontario and Alberta. One focus group was convened in Ontario and Alberta, and two focus groups in Montreal, Quebec, to address potential differences in the perspectives of francophone and anglophone populations.

Data Collection

A moderator's guide was formulated in consultation with clinical experts and qualitative research specialists. The guide included open-ended questions on the following topics of interest: disease self-management, personal experience with IBD care services and individual's perspectives of services that would be provided in an ideal IBD clinic setting. The list of questions was published in our previous work (8). The focus groups were moderated by four nurses with experience in IBD; the nurses played an important part in facilitating and guiding the discussion and making sure all participants expressed their views.

All focus group discussions were audio-recorded and the audio files were transferred to a computer for storage and transcription.

Data Processing and Analysis

Two coders (M.V. and N.K.) derived all themes from participants' accounts using the verbatim transcript. Three of the four nurse moderators assisted with the development of the initial themes extracted from the focus groups they mediated.

Themes were coded in three steps. First, coding was done independently by each coder, using the key phrases mentioned at least once, for example, 'need for information'. In a second step, similar codes were grouped and categorized. The final step consisted in performing the necessary adjustments of coding trees to obtain the final themes, which were confirmed by both coders.

The RQDA package in R (11) was used for transcript analysis, to identify main themes and to build a theme hierarchy based on the number of citations.

Ethical Issues—Consent and Confidentiality

Crohn's and Colitis Canada, as part of the PACE program, organized the convening of the focus groups using its existing database of Canadian IBD patients who consented to be contacted with IBD-related correspondence. Confidentiality agreements were signed by all members of the research staff involved in the project. At the beginning of each focus group discussion, the patients were informed about the specifics of the project and signed an informed consent form. Patients were made aware that their participation is voluntary and that they can withdraw from the discussion at any point. All patients completed an anonymous demographic questionnaire. The transcripts of the four audio recordings were anonymized such that the analysts' copies showed only 'moderator', 'male respondent' or 'female respondent' as identifiers.

RESULTS

A total of 26 participants (M:F 1:1.9, average age: 41.3 years) took part in the focus group discussions, 14 in Montreal, Quebec, 5 in Toronto, Ontario and 7 in Calgary, Alberta. The demographic characteristics are presented in Table 1. The age distribution was very similar for Crohn's disease (CD) and ulcerative colitis (UC). The majority of participants were women and approximately 65% were living with their disease for more than 5 years at the time of the discussions. There

Table 1. Demographic characteristics of participants (N = 26)

Characteristics	Total	CD	UC
Age (mean ± SD)	41.3 ± 14.9	41.3 ± 13.7	41.3 ± 19
Male (%)	34.6	31.6	42.9
Years since diagnosis, years (%)			
<1	11.5	10.5	14.3
1–2	11.5	10.5	14.3
2–5	11.5	5.3	28.6
5–10	19.2	15.8	28.6
10–20	15.4	21.1	0
>20	30.8	36.8	14.3

CD, Crohn's disease; UC, Ulcerative colitis.

were no significant differences in mean age and sex distribution between the three provinces where the groups were convened.

The Supplementary Table 1 presents the 14 main themes that emerged from the focus group discussions; themes were derived from issues raised in at least three of the four focus group discussions.

Access to Multidisciplinary IBD Care Services

This was the most frequently recurring composite theme, with 112 references overall. Multidisciplinary care services referred to medical specialists other than gastroenterologists, such as dermatologists, ophthalmologists, rheumatologists, family physicians, obstetrician/gynecologists and dentists, as well as to complementary services (dietician/nutritionist, pharmacist and physiotherapist) or even nontraditional medicine practitioners (naturopath, osteopath, acupuncturist and yoga coach). In patients' view, the ideal IBD clinic would offer access to all traditional and nontraditional medical specialists to help in the management of complications and comorbidities.

Information

Information was the most frequently recurring individual theme, with 65 references overall. The lack of sufficient information regarding the disease and its impact on the quality of life was a current frustration and something patients expect to receive in an ideal IBD clinic setting, from their IBD care specialist, nurses or other staff members.

Support for Self and Family/Caregivers

There were 43 references to support for self or for the caregivers. Patients living with IBD for more than 10 to 15 years had not benefited from any professional support at the time of their diagnosis. Those diagnosed more recently, claimed that even if

support was available through various organizations, the information regarding such programs was not readily available to them.

Access to Psychological/Psychiatric/Mental Health Support/Social Worker

There were 40 references to mental health care or social work support for themselves or their caregivers. The patient perspective reflects an unmet need related to specialized assistance to cope with disease impact on health, quality of life (personal life, career, body image, medication compliance, pain management, etc.), the prospect of surgical interventions and cancer development.

Access to Medical File Information (i.e., test results, lab/scope reports, EMR) for Patients and Other Treating Physicians

The need for access to medical file information was mentioned 30 times. Specific reference addressed access to lab results and colonoscopy summaries by both the patient and medical specialists, other than the treating GI physician, involved in their care.

Reduce Disease Impact on Overall Health, Coping, Quality of Life and Career

There were 30 references related to the patients' perceived ability to cope with or reduce the impact of the disease on their quality of life. The responses varied widely on issues such as ability to adhere to the treatment plan, diet adjustments or to cope with impact on their personal and professional lives.

Access to GI Specialist/IBD Care, Reduced Patient Load for Specialists

The need to be able to reach the treating GI specialist was mentioned 29 times. The responses varied between easy access through personal email or phone communication and total lack of access leading to frequent visits to the emergency room.

Patient-Centered Treatment Plan

The need to be included in decisions regarding the treatment plan was mentioned 24 times. The patients expressed their frustration with feeling left out of the treatment decisions, not being listened to when it came to side effects of medication or corticodependence.

Patient Perception of IBD Care Staff: Friendly, Caring, Supportive and Empathic

References to the staff's manner of approach were made 20 times. The responses varied widely, between perceived empathy and support to feeling disrespected or eagerly dismissed.

Access to IBD Nurse

The need to access an IBD nurse was mentioned 17 times. Patients expressed satisfaction with the information provided and the timeliness of response when access to an IBD nurse was enabled. The need to contact a nurse came up mostly in the context of a change in symptoms which led to uncertainties regarding the dosing of medication or the need to present to the emergency room. Access to an IBD nurse was perceived as a must-have in an ideal IBD clinic setting.

Reduced Diagnosis/Treatment Delays

There were 14 references to delays in receipt of a diagnosis or treatment. The patients reported delays varying from a couple of months to several years.

Medication Adherence

There were 13 references to medication adherence. In general, patients reported being compliant to their treatment regimen, albeit with difficulties for some.

Chronic Pain Management

The need for pain management was mentioned 13 times. Patients expressed a dire need for pain medication, some needing the medication even during remission. Patients reported that their treatment plan did not necessarily include pain medication.

Use of Technology (i.e., apps, online resources, etc.)

There were 11 mentions regarding the use of various online applications. Patients expressed interest in applications that enabled them to track symptoms and use of medication.

The quality indicators included in the PACE program that were matched to the main themes identified from the patient focus groups are presented in Table 2. A total of nine patient-derived quality indicators met the importance criteria for inclusion in the final list of 45 quality indicators of the PACE program (8).

Discussion

This qualitative study used patient focus groups as an indirect involvement approach to capture the perspective of patients on IBD care services. Our findings identified several perceived unmet needs amenable for conversion to measurable quality indicators. The most frequently reported unmet needs addressed mainly the need for information and access to multidisciplinary services, specialized IBD care, medical file information and psychological support. These issues were raised in at least three of the four focus groups, regardless of location site.

Our results are similar to those observed in studies elsewhere. A survey of IBD specialists from 41 countries showed a lack of structured patient support and a need for multidisciplinary care teams in IBD excellence centres (12). A survey of 355 IBD patients indicated increased satisfaction with the services provided among those involved in a process of shared decision-making regarding their treatment plan (13). Two multicentric studies in Italy and Spain involving 450 and 290 patient participants, respectively, revealed that, despite the high level of satisfaction with IBD care, the information received from health care providers was perceived as insufficient (14,15) and the communication among medical specialists was perceived as problematic (15). The two most important expectations identified by the 1094 patients enrolled in a recent survey of a Swiss IBD cohort were the good communication between the treating physician and other specialists, and receipt of appropriate information on the adverse effects of treatment (16).

This study has limitations. We did not perform a comparison of results by sex, type of IBD or disease duration, as our aim was to address all issues of interest rather than examine variability in care. The results reflect the perception and the IBD care experience of the study participants. Volunteer bias is a well known challenge to generalizability of results in research studies eliciting patient perspectives, as the participants may differ in key aspects from the target population.(17) Our

Table 2. Quality indicators in the final set mapped to main themes emerging from focus group discussions

Structure QIs	The IBD Unit/Clinic has access to all of the following health care professionals: pharmacist, ophthalmologist, rheumatologist, obstetrician and dermatologist
	The IBD Unit/Clinic has access to all of the following health care professionals: dieticians, mental health worker/psychologist, stoma therapist
	The IBD Unit/Clinic has a dedicated IBD nurse
	The IBD Unit/Clinic has access to a surgical program that performs at least 10 ileoanal pouch operations a year
	The IBD Unit/Clinic has access to a fellowship trained colorectal surgeon
Process QIs	Referring and family physician (if not referring) are updated on their patient's condition at each visit
	The IBD Unit/Clinic has a formal process for transfer of care from pediatric to adult
	IBD patients are directed to educational information
	The IBD Unit/Clinic has a mechanism to screen for mental health issues

IBD, Inflammatory bowel disease; QI, Quality indicator.

study participants were a convenience sample drawn from the Crohn's and Colitis Canada database of IBD patients. However, this database includes all patients which agreed to be contacted by Crohn's and Colitis Canada, without any requirement for active involvement in Crohn's and Colitis Canada's activities. Furthermore, the specific objectives of the research project were presented to the participants only prior to the focus group discussion. We took several additional steps to facilitate the generalizability of the findings in our present study, such as patient selection from various geographical settings, balanced by age, sex, type of IBD and disease duration and bilingual discussions, guided by open-ended questions. As anonymity and confidentiality are essential in reducing the potential impact of volunteer bias (17) two researchers independently analyzed the data using anonymized transcripts.

CONCLUSION

Our study provides a detailed description of patient perspectives on IBD care services that were integral to the development of measurable indicators of the quality of care within the context of a publicly funded universal-access health care system. Assessment of these indicators across Canadian IBD centres will be instrumental to evaluating in which degree the PACE program has contributed to an increase in the quality of health care services.

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Author Contributions

M.V., M.S.[2], G.C.N. and A.B. had a significant contribution in the conception and the design of the study, in data interpretation and revised the manuscript for important intellectual content. M.V. drafted the manuscript and had a major contribution in data analysis. N.K., M.S.[1], I.M., S.B., J.H. and K.S.D. had a significant contribution in data collection and revised the manuscript for important intellectual content. All authors reviewed and approved the final version of the manuscript

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Conflict of Interest

The authors report no conflicts of interest related to this work.

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