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EDITOR'S CHOICE

Identification and prioritization of patient-centred strategies to enhance IBD-related care for older adults: a modified Delphi approach

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Abstract

Background: The older adult age group makes up one of the fastest-growing groups of individuals with inflammatory bowel disease (IBD). It is important to hear the perspectives of older adults living with IBD about care experiences and managing their illness. The purpose of this patient-oriented study was to identify and prioritize patient-centred strategies that have the potential to enhance IBD-related care for older adults in Saskatchewan.

Methods: The interprofessional research team, consisting of older adult individuals living with IBD, gastroenterology providers, and researchers specializing in IBD or older adult education used a modified Delphi approach to identify and prioritize strategies that may enhance IBD-related care for older adults. Thirty-one older adults with IBD participated in ranking, revising, and prioritizing statements related to their chronic illness care. Nine statements were developed that highlighted strategies for older adult IBD care.

Results: Through the consensus process, 6 statements were retained. Co-creating a treatment plan with the IBD provider was ranked as the top priority statement for older adults with IBD.

Conclusion: Facilitating collaborative relationships and understanding individual priorities for IBD-related care for older adults has the potential to enhance positive health outcomes and quality of life for these individuals.

Key words: inflammatory bowel disease; older adults; chronic illness care; modified Delphi.

Background

Canada has over 322,000 individuals living with inflammatory bowel disease (IBD).[1] The older adult age group (≥60 years) makes up one of the fastest-growing groups of individuals living with IBD due to the number of new diagnoses as well as more individuals moving into this age group.[2] It is estimated that 1 in 88 older adults in Canada has IBD.[3] Medical management of IBD in older adults is similar to management in other age groups.[2] However, management of care can be complex, due to the presence of comorbidities, polypharmacy, and the natural ageing process experienced by these individuals. While there has been considerable literature focusing on the epidemiological aspects and medical management of IBD care, there has been little attention given to the care experiences of and perspectives of older adults living with IBD. With the move towards patient and family-centred care, it is important to hear the perspectives of older adults with IBD about care experiences and managing their illness.

In a recent scoping review on the experiences of older adults living with IBD, a predominant element across all studies was the preference for individualized, patient-centred care.[4] Integrated models of care were seen as ideal for providing patient-centred care[5,6] and these models were often built upon the chronic care model (CCM) framework to guide service delivery and to support persons with chronic conditions in the community. Within the CCM framework, complex interactions among the community, health system, persons with chronic illness, and the healthcare team were noted.[7,8]

The *Patient Assessment of Chronic Illness Care* (PACIC) instrument is derived based on the CCM framework and assesses patient perspectives on their chronic illness care and emphasizes patient-healthcare team interactions.[9] The scale has demonstrated good reliability and validity and reports on

the extent to which patients have received certain actions and care that are congruent with the CCM.[9] The scale consists of 20 items each scored on a 5-point Likert scale with higher scores representing greater perceived patient-centred care. Based on findings from 2 Canadian studies assessing chronic illness care for older adults with IBD using the PACIC instrument, it was found that older adults with IBD perceive limited collaborative IBD management and communication between older adults and the providers within the health system.[10,11] Given this perception of identified gaps in collaborative IBD management by older adults with IBD, further investigation is needed related to the identification and prioritization of elements to enhance patient-centred IBD care management and communication. Patient preference and goals must guide IBD-related care[12] as persons with lived experience are the experts in recognizing what information and services are needed to enhance their chronic illness care. The purpose of this patient-oriented project was to identify and prioritize patient-centred strategies that have the potential to enhance IBD-related care for older adults in Saskatchewan.

Methods

Research design

The interprofessional research team, consisting of older adult individuals living with IBD, gastroenterology providers, and researchers specializing in IBD or older adult education used a modified Delphi approach to identify and prioritize strategies that have the potential to enhance IBD-related care for older adults.[13] All members of the research team, including individuals with lived experience, were equal, contributing members in every aspect of the research process. However, gastroenterology provider team members did not have access to raw, individual data to protect participants who may be cared for by the provider team members.

The aim of a Delphi approach is to seek expert opinion on a specific topic.[14] In this study, older adults with IBD were considered the experts whose opinion was required to identify priorities for care. A modified approach was used as participants were provided with the PACIC survey statements as a starting point to work from. As mentioned above, 2 past studies explored older adult perspectives of chronic illness IBD care and gaps in that care were identified. Thus, these survey statements became the expert panel's basis on which to start working. The informational materials and statements were reviewed and piloted by the research team in advance of data collection. No changes were made. This Delphi project was not prospectively registered.

The goal of utilizing the Delphi approach is to determine expert consensus when experimental methods are not feasible.[13] However, the consensus level for each study varies due to the definition of consensus established by each research team.[13] Through the modified Delphi approach, participants rate each statement on a Likert scale to indicate their level of agreement. Panel members are provided with the opportunity to suggest alternate statements as they complete the rankings.[13] Summarized, de-identified rankings are provided to participants to showcase the overall panel rankings. This process of statement ranking, collating the data, sharing the findings, and re-ranking occurs until consensus is reached.

Setting, sample, and recruitment

The study was conducted in Saskatchewan, Canada. The inclusion criteria were English-speaking older adults (≥60 years) with a diagnosis of Crohn's disease or ulcerative colitis. After ethical approval (University of Saskatchewan, BEH #3574), convenience sampling was used for recruitment which occurred between October 2022 and January 2023. All participants in a recent study on older adults with IBD in Saskatchewan[10] were invited to participate along with recruitment from 2 gastroenterologists' offices. The 2 research team members who were persons with lived experience were also eligible to participate. Interested participants contacted the principal investigator (PI) or research trainee, were screened for eligibility, and consented to the project. The PI was responsible for determining participant selection and inclusion, based on eligibility criteria. Thirty-one participants, who met the inclusion criteria, volunteered to participate and this number is considered an appropriate sample size for Delphi studies.[15] No incentives to participate were provided to participants.

Data collection and analysis

Voluntary demographic information was collected from all participants and descriptive statistics were completed. Participants were asked about the *frequency* with which each of the 20 PACIC scale items occurred (1 = none of the time to 9 = always). The consensus process consisted of 3 rounds occurring between October 2022 and May 2023 including ranking of statements (Round 1—October 2022 to February 2023), facilitated online discussion (Round 2—March 2023), and final rankings of revised statements (Round 3—April to May 2023). In Rounds 1 and 3, participants completed the rankings online via SurveyMonkey, via mailed paper survey with a postage-paid return envelope, or via verbal response to the research trainee. Paper and verbal responses were manually inputted into the SurveyMonkey system. Reminders for survey completion for Rounds 1 and 3 were sent via email or telephone to participants by the research trainee. Participants were asked to rank each statement on its *importance* to their IBD care (1 = extremely unimportant to 9 = extremely important). The research team decided in advance that statements ranked with medians between 7 and 9 would be kept, statements with medians between 4 and 6 would be discussed in Round 2, and statements with medians between 1 and 3 would be discarded. In each round, all participants were invited to participate, and opportunities were provided to change or edit any of the statements during each round. See Figure 1 for an overview of each round.

Round 1 consisted of ranking each of the 20 PACIC statements on their *importance* to IBD care. Once rankings were received, means, standard deviations, medians, and interquartile ranges were reported for each statement. No changes to the statements were suggested by participants during the Round 1 process.

Round 2 involved a pre-recorded introductory session given by 3 of the research team members (N.R., J.-N.P.-S., and N.T.) to explain the preliminary grouped, de-identified rankings from Round 1 and to provide an explanation as to what was expected during Round 2. Following the pre-recorded session, there were 2 live facilitated online Zoom discussions where participants learned about the Round 1 grouped, de-identified ranking results, had an opportunity to discuss all statements (particularly those that had medians between 4 and 6), and provided suggestions for editing the statements. All research team members where present during
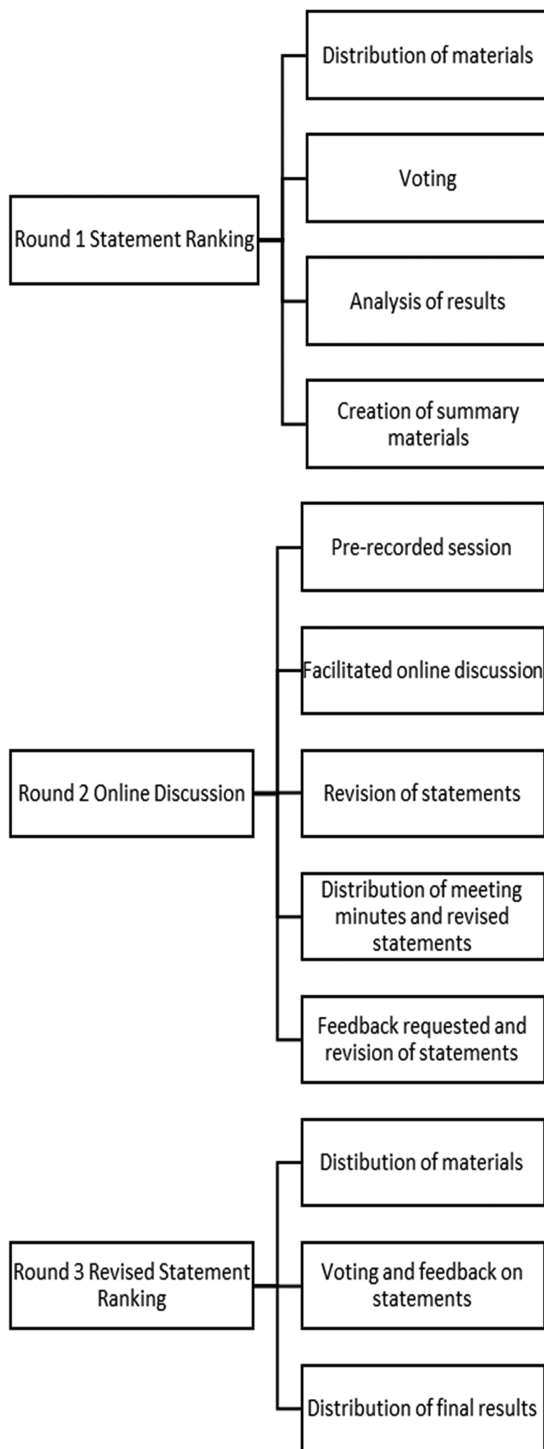
Figure 1. Modified Delphi process flow chart.

the 2 online discussions. Based on participant feedback, some statements were revised, merged, and grouped into categories for a total of 9 revised statements. Two live online sessions were conducted to accommodate participant schedules and encourage maximum participation. Meeting minutes and a copy of the 9 revised statements were distributed to all 31 participants before Round 3. Participants were asked for feedback on the draft revised statements with the following prompting questions: (1) were the changes to the statements captured appropriately, (2) do the newly created statements

reflect the priorities for IBD-related care for older adults, and (3) are there any suggestions for change to the statements.

During **Round 3**, all participants were asked to rank the revised 9 statements on their *importance* to IBD care. Once rankings were received, means, standard deviations, medians, and interquartile ranges were obtained for each of the statements. Cronbach's alpha was computed to test the internal consistency for the 9 statements. The research team's a priori determination of consensus was: (1) that the statement item had a median score between 7 and 9; and (2) 75% of participants scored the statement item with a median score of 7 and above.[16] Finally, participants were asked to rank the 9 revised statements in perceived priority order for IBD care for older adults (1 = most important to 9 = least important).

Results

Participant demographics and frequency of occurrence

The demographic characteristics of study participants are presented in Table 1. Most participants were female ($n = 20$, 64.5%), were in the age range of 65–69 years ($n = 13$, 41.9%), and were diagnosed with IBD before 60 years of age ($n = 22$, 73.3%). Regarding the *frequency* with which each of the initial 20 PACIC statements occurred in their routine IBD care (1 = none of the time to 9 = always), all but 2 of the statements had medians of 3 or less, representing a low frequency of occurrence. Statements '*satisfied that my care was well organized*' (median = 6, IQR = 3.5–7) and '*asked to talk about any problems with my medicines or their effects*' (median = 6, IQR = 3–8) had the highest medians. See Table 2.

Round 1 rankings

Participants ranked each of the 20 statements on their *importance* to their IBD care (1 = extremely unimportant to 9 = extremely important). See Table 3. The highest ranking was regarding the statement, '*satisfied that my care was well organized*' (median = 8, IQR = 7–9) and the lowest ranking was associated with the statement, '*encouraged to go to a specific group or class to help me cope with my chronic condition*' (median = 5, IQR = 1–7).

Round 2 online discussion

Fifteen participants attended the online 90-minute sessions to discuss the Round 1 group ranking results and provide suggestions for statement revision. All statements were discussed with priority discussion occurring on the items with median rankings between 4 and 6. All members expressed that they did not want any statements removed from the list. They did, however, provide suggestions to create new, merge, or alter the statements to consolidate them. Based on participant feedback, statements were created, revised, merged, and grouped into categories (Planning, Goals and Self-Care, Clinical Visits, and Programs) for a total of 9 revised statements. See Table 4. Participants reviewed and approved the final 9 statements prior to Round 3. Cronbach's alpha for the final nine statements was 0.927.

Round 3 rankings

Twenty-five (81%) participants completed Round 3. Reasons for participant attrition were other commitments ($n = 2$); no

Table 1. Demographics (*n*=31).

Characteristics	*n* (%)
Sex	
Male	11 (35.5)
Female	20 (64.5)
Age group	
60-64 years	4 (12.9)
65-69 years	13 (41.9)
70-74 years	9 (29.0)
74-79 years	4 (12.9)
80-84 years	1 (3.3)
Diagnosis	
Crohn's disease	16 (51.6)
Ulcerative colitis	12 (38.7)
Unsure of type of IBD diagnosis	3 (9.7)
Age of diagnosis*	
Before age 60	22 (73.3)
After age 60	8 (26.7)
Disease duration (years)*	
0-4	4 (12.9)
5-9	6 (19.4)
10-14	3 (9.7)
15-19	6 (19.4)
≥20	10 (32.3)
Location of residence	
Central Saskatchewan	5 (16.1)
Saskatoon and surrounding area	6 (19.4)
Regina and surrounding area	13 (41.9)
Southern Saskatchewan	7 (22.6)
Main HCP (select all that apply)**	
Gastroenterologist	27 (87)
General/family practitioner	11 (35.4)
Other	6 (16.3)
Surgeon	4 (12.9)
Nurse clinician	3 (9.7)
How often do you see that HCP?	
Every 1-6 months	12 (38.7)
7-12 months	13 (41.9)
≥13 months	6 (19.3)
IBD well-controlled in last 2 weeks	
Yes	22 (71.0)
No	9 (29.0)
Current treatment useful	
Yes	28 (90.3)
No	3 (9.7)
Overall control of IBD in the past 2 weeks (0 = worst possible control, 10 = best possible control)	
0-3	2 (6.5)
4-6	9 (29.0)
7-10	20 (64.5)
Satisfaction with current IBD care (0 = completely dissatisfied, 10 = completely satisfied)	
0-3	2 (6.5)
4-6	8 (25.8)
7-10	21 (67.7)

*Missing values; **proportions may not equal 100% as participants could select more than one answer.

response (*n* = 2); illness (*n* = 1); and refusal with no reason provided (*n* = 1). Participants were asked to rank each of the 9 revised statements on their *importance* (1 = extremely unimportant to 9 = extremely important). See Table 5. Two statements had the highest ranking scores: '*co-create a treatment plan (including short-term and long-term goals) with my IBD provider that takes into consideration my personal goals, receive a written copy of this treatment plan, ensure my understanding of this plan, and review the plan with my IBD provider on an ongoing basis*' (median = 9, IQR = 8–9) and '*contacted by my IBD provider after a visit to follow up to see how things were going, especially after changes in my therapy, medication, surgery, etc.*' (median = 9, IQR = 8–9). The lowest ranking score was associated with the statement, '*encouraged to attend community groups, classes, or programs to help me learn more about and self-manage my IBD*' (median = 7, IQR = 5–8). Participants were provided an opportunity to indicate their rationale for ranking each statement as they did. For one of the statements with the highest importance, participants expressed that a treatment plan should be co-created and provided in written format to ensure they understand what is expected in their disease course and to ensure no information was forgotten from the appointment. Participants also stated that co-creating a treatment plan strengthened their relationship with their IBD healthcare provider. Regarding the second highest ranked statement, participants believed it was important to have follow-up in case they had questions, were unsure of if side effects or symptoms were normal, and to demonstrate care towards the person with IBD. For the statement participants identified as the least important, participants stated that they were uncomfortable in a group setting and that over the years they have developed adequate support systems. Thus, group classes were not beneficial for participants. Greater than 75% consensus was reached on six of the nine statements (see Table 5).

Participants were then asked to place those same 9 statements in *priority order* (1 = most important to 9 = least important) see Table 6. The statement with the highest priority ranking was '*co-create a treatment plan (including short-term and long-term goals) with my IBD provider that takes into consideration my personal goals, receive a written copy of this treatment plan, ensure my understanding of this plan, and review the plan with my IBD provider on an ongoing basis*' (median = 1, IQR = 1–3). The statement with the lowest priority ranking was '*encouraged to attend community groups, classes, or programs to help me learn more about and self-manage my IBD*' (median = 9, IQR = 8–9). Participants were provided an opportunity to indicate their rationale for prioritizing the first and last priority statements as they did. The participants described the co-creation of the treatment plan as the highest priority statement for patients to understand their specific disease and co-manage their treatment with their healthcare provider. Reasons for choosing the lowest priority statement were that participants did not like and were uncomfortable with group classes, the sessions often resulted in 'complaining', they were not available in their area, and discussions between patients and providers should occur first.

Discussion

The objective of this study was to identify and prioritize patient-centred strategies that have the potential to enhance IBD-related care for older adults. In this research,

Table 2. Descriptive statistics of the patient assessment of chronic illness care (PACIC) statements rankings by frequency of occurrence in IBD healthcare for older adults.

Statement	*n*	Median (IQR)	Mean (SD)
Asked to talk about any problems with my medicines or their effects	31	6 (3-8)	5.65 (2.72)
Satisfied that my care was well-organized	31	6 (3.5-7)	5.52 (2.76)
Given a choice about treatment options to think about	31	3 (1-5.5)	3.94 (2.84)
Asked for my ideas when we made a treatment plan	31	3 (1-5.5)	3.61 (2.72)
Shown how what I did to take care of myself influenced my condition	31	3 (1-6)	3.52 (2.66)
Helped to make a treatment plan that I could carry out in my daily life	30	2.5 (1-7)	3.93 (3.19)
Sure that my doctor or nurse thought about my values, beliefs, and my traditions when they recommended treatments to me	30	2 (1-5)	3.53 (2.98)
Contacted after a visit to see how things were going	31	2 (1-4.5)	3.13 (2.58)
Asked how my chronic condition affects my life	31	2 (1-5)	3.03 (2.65)
Helped to plan ahead so I could take care of my condition even in hard times	31	2 (1-5)	3.03 (2.50)
Asked questions, either directly or on a survey about my health habits	31	2 (1-5)	2.84 (2.21)
Asked to talk about my goals in caring for my illness	30	1.5 (1-3)	2.67 (2.44)
Helped to set specific goals to improve my eating or exercise	31	1 (1-2.5)	2.55 (2.51)
Given a written list of things I should do to improve my health	31	1 (1-3)	2.39 (2.29)
Given a copy of my treatment plan	31	1 (1-2.5)	2.35 (2.36)
Referred to a dietitian, health educator, or counsellor	31	1 (1-2)	2.00 (1.86)
Told how my visits with other types of doctors, like the eye doctor or other specialist helped my treatment	30	1 (1-1)	1.93 (2.23)
Asked how my visits with other doctors were going	28	1 (1-1)	1.79 (2.02)
Encouraged to go to a specific group or class to help me cope with my chronic condition	31	1 (1-1.5)	1.55 (1.39)
Encouraged to attend programs in the community that would help me	30	1 (1-1)	1.27 (0.69)

*Rating scale (1 = none of the time, 9 = always); IQR = interquartile range; SD = standard deviation.

Table 3. Descriptive statistics of patient assessment of chronic illness care (PACIC) statements by importance in IBD healthcare for older adults.

Statement	n	Median (IQR)	Mean (SD)
Satisfied that my care was well-organized	31	8 (7-9)	7.65 (1.80)
Asked to talk about any problems with my medicines or their effects	31	8 (7-9)	7.52 (2.16)
Asked how my chronic condition affects my life	31	8 (7-9)	7.10 (2.76)
Asked for my ideas when we made a treatment plan	31	8 (5.5-9)	6.93 (2.38)
Given a copy of my treatment plan	31	8 (6.5-8)	6.68 (2.59)
Helped to plan ahead so I could take care of my condition even in hard times	31	8 (5.5-9)	6.61 (2.99)
Given choice about treatment options to think about	31	7 (7-9)	7.06 (2.24)
Shown how what I did to take care of myself influenced my condition	30	7 (6.3-8)	6.77 (2.40)
Asked to talk about my goals in caring for my illness	31	7 (5.5-8.5)	6.74 (2.19)
Helped to set specific goals to improve my eating or exercise	31	7 (5-9)	6.61 (2.47)
Contacted after a visit to see how things were going	31	7 (5-8.5)	6.52 (2.61)
Sure that my doctor or nurse thought about my values, beliefs, and my traditions when they recommended treatments to me	29	7 (5-9)	6.38 (2.62)
Given a written list of things I should do to improve my health	31	7 (5-8)	6.32 (2.66)
Helped to make a treatment plan that I could carry out in my daily life	31	7 (3-9)	6.03 (3.06)
Asked how my visits with other doctors were going	31	7 (4.5-8)	5.90 (2.60)
Asked questions, either directly or on a survey about my health habits	31	7 (3-8)	5.68 (2.87)
Told how my visits with other types of doctors, like the eye doctor or other specialist helped my treatment	31	6 (5-8)	5.90 (2.56)
Referred to a dietitian, health educator, or counsellor	31	6 (4-8)	5.61 (2.75)
Encouraged to attend programs in the community that would help me	31	5 (1.5-7)	4.74 (2.90)
Encouraged to go to a specific group or class to help me cope with my chronic condition	31	5 (1-7)	4.58 (3.00)

*Rating scale (1 = extremely unimportant, 9 = extremely important); IQR = interquartile range; SD = standard deviation.

Table 4. Original patient assessment of chronic illness care (PACIC) and revised statements in IBD healthcare for older adults.

Original statements	Revised statements
	Category: planning
1. Asked for my ideas when we made a treatment plan	1. Co-create a treatment plan with my IBD provider that takes into consideration my personal goals, receive a written copy of this treatment plan, ensure my understanding of this plan, and review the plan with my IBD provider on an ongoing basis.
2. Given a copy of my treatment plan	
3. Helped to make a treatment plan that I could carry out in my daily life	
4. Asked to talk about my goals in caring for my illness	
5. Sure that my doctor or nurse thought about my values, beliefs, and my traditions when they recommended treatments to me	
6. Satisfied that my care was well organized	
7. Asked to talk about any problems with my medicines or their effects	
8. Given choice about treatment options to think about	
9. Asked how my chronic condition affects my life	
* Be sure that the doctor knows that I understand the treatment plan	
	Category: goals and self-care
10. Given a written list of things I should do to improve my health	2. Given a written list of resources and ideas to self-manage my IBD and improve my health in areas including eating, exercise, pain management, medication, and additional provider suggestions.
11. Helped to set specific goals to improve my eating or exercise	
12. Shown how what I did to take care of myself influenced my condition	
13. Helped to plan ahead so I could take care of my condition even in hard times	3. Helped to plan ahead to help manage changes in my condition.
14. Asked questions, either directly or on a survey about my health habits	4. Asked questions about my health habits (diet, exercise, stress, mental health, etc.).
	Category: clinical visits
15. Asked how my visits with other doctors were going	5. Discuss with my IBD provider the roles and responsibilities of the different professionals involved in my care, discuss how these visits are going, and how they help with my treatment
16. Told how my visits with other types of doctors, like the eye doctor or other specialist helped my treatment	
* Understand the responsibilities of the different healthcare professionals	
17. Contacted after a visit to see how things were going	6. Contacted by my IBD provider after a visit to follow up to see how things were going, especially after changes in my therapy, medication, surgery, etc.
18. Referred to a dietitian, health educator, or counsellor	7. Referred to additional healthcare providers such as a dietitian, health educator, or counsellor if needed
* Able to communicate with my IBD healthcare provider in a timely manner	8. Able to communicate with my IBD healthcare provider in a timely manner
	Category: programs
19. Encouraged to go to a specific group or class to help me cope with my chronic condition	9. Encouraged to attend community groups, classes, or programs to help me learn more about and self-manage my IBD
20. Encouraged to attend programs in the community that would help me	

*Newly created item suggested by participants during the Round 2 process.

older adults prioritized being actively involved in their IBD care through the co-creation and ongoing evaluation of the treatment plan as a shared process with providers. The top 3 prioritized statements focus on the importance of a collaborative relationship between IBD providers and persons living with IBD. This prioritization of a co-created treatment plan and a collaborative relationship between provider and patient can be described as utilizing a shared decision-making approach. Shared decision-making is defined as the collaborative process in which the patient and provider make decisions together that are inclusive of patient preferences.[17–21] This individualized and patient-centred approach to IBD care delivery was highlighted as important by persons living with IBD in a recent Canadian study.[22]

It is important to note that the top 3 prioritized statements focus on the relationship between the healthcare provider and the older adult living with IBD. Research has shown that the quality of the relationship between providers and patients influences the degree of patient involvement.[23] The better the relationship, the higher the degree of involvement. Having trust in the provider and feeling cared for and listened to are also components that impact the willingness to be engaged in decision-making processes.[23]

Table 5. Descriptive statistics of the 9 revised statements in IBD healthcare for older adults by importance.

	n	Median (IQR)	Mean (SD)	Consensus median score between 7 and 9 *n* (%)
Co-create a treatment plan (including short-term and long-term goals) with my IBD provider that takes into consideration my personal goals, receive a written copy of this treatment plan, ensure my understanding of this plan, and review the plan with my IBD provider on an ongoing basis.	25	9 (8-9)	7.84 (1.86)	20 (80%)
Contacted by my IBD provider after a visit to follow up to see how things were going, especially after changes in my therapy, medication, surgery, etc.	25	9 (8-9)	7.84 (2.13)	21 (84%)
Given a written list of resources and ideas to self-manage my IBD and improve my health in areas including eating, exercise, pain management, medication, and additional provider suggestions.	25	8 (7-9)	7.72 (1.99)	21 (84%)
Able to communicate with my IBD healthcare provider in a timely manner.	25	8 (7-9)	7.68 (1.82)	21 (84%)
Helped to plan ahead to help manage changes in my condition.	25	8 (7-9)	7.44 (1.96)	19 (76%)
Asked questions about my health habits.	25	8 (7-9)	7.32 (2.12)	19 (76%)
Referred to additional healthcare providers such as a dietitian, health educator, or counsellor if needed.	25	8 (6-9)	6.84 (2.58)	17 (68%)
Discuss with my IBD provider the roles and responsibilities of the different professionals involved in my care, discuss how these visits are going, and how they help with my treatment.	25	7 (6-9)	6.8 (2.52)	17 (68%)
Encouraged to attend community groups, classes, or programs to help me learn more about and self-manage my IBD.	25	7 (5-8)	5.72 (2.70)	14 (56%)

*Rating scale (1 = extremely unimportant, 9 = extremely important); IQR = interquartile range; SD = standard deviation.

Table 6. Descriptive statistics of the final 9 revised statements in IBD healthcare for older adults by priority order.

Statement	*n*	Median (IQR)	Mean (SD)
Co-create a treatment plan (including short- and long-term goals) with my IBD provider that takes into consideration my personal goals, receive a written copy of this treatment plan, ensure my understanding of this plan, and review the plan with my IBD provider on an ongoing basis.	25	1 (1-3)	2.12 (1.67)
Contacted by my IBD provider after a visit to follow up to see how things were going, especially after changes in my therapy, medication, surgery, etc.	25	4 (2-5)	3.76 (1.79)
Able to communicate with my IBD healthcare provider in a timely manner.	25	4 (2-6)	4.24 (2.39)
Given a written list of resources and ideas to self-manage my IBD and improve my health in areas including eating, exercise, pain management, medication, and additional provider suggestions.	25	5 (3-6)	4.68 (2.27)
Helped to plan ahead to help manage changes in my condition.	25	5 (3-6)	4.92 (2.31)
Asked questions about my health habits.	25	5 (3-7)	5 (2.43)
Discuss with my IBD provider the roles and responsibilities of the different professionals involved in my care, discuss how these visits are going, and how they help with my treatment.	25	6 (4-7)	5.72 (2.35)
Referred to additional healthcare providers such as a dietitian, health educator, or counsellor if needed.	25	6 (5-8)	6.36 (1.75)
Encouraged to attend community groups, classes, or programs to help me learn more about and self-manage my IBD.	25	9 (8-9)	8.2 (1.32)

*Rating scale (1 = most important to 9 = least important); IQR = interquartile range; SD = standard deviation.

Communication, between providers and older adults with IBD, is also an important element within the top 3 prioritized statements. Effective reciprocal communication between providers and persons with IBD and ensuring an understanding of treatment and disease management information results in increased satisfaction with treatment decision-making.[18,19,24] As a result of effective communication and understanding, persons with IBD are better able to make informed decisions related to their care.

The need for information related to IBD was seen as important to individuals in this study, as evidenced by a higher (top 4) ranking of the statement '*given a written list of resources and ideas to self-manage my IBD and improve my health*'. The key information needs for persons living with IBD in the literature are related to nutrition, medication, and treatment options.[25] By knowing information on these specific topics, persons with IBD can better self-manage their disease. However, the source of the information also influenced the rankings as the lowest priority item was related to '*attending groups, classes, or programs to help learn more about and self-manage IBD*'. Participants expressed they did not like group environments and felt information should come from IBD providers. The preference for seeking information related to IBD from providers was also noted in other studies.[22,25,26]

Greater health literacy, that is understanding health information to make appropriate healthcare decisions, regarding IBD results in more positive patient-reported health outcomes.[27]

Implications for practice

Most providers are supportive of shared decision-making, particularly when persons living with illness want to be involved in the process and where multiple treatment options exist.[28] However, both providers and persons living with illness report barriers such as a lack of resources and time to fully engage in shared decision-making.[20,29] Also, shared decision-making may not be appropriate in all situations for all persons with IBD.[30] To start the shared decision-making process and mitigate the barriers, providers could provide the list of 6 final statements and ask persons living with IBD to prioritize them or add additional statements to determine what the priority is for each patient with the goal of achieving individualized, patient-centred care. An alternative would be to provide the list of final statements and ask the person with IBD what matters most to them. By asking persons with IBD what matters most, prioritized goals of care can be illuminated[31] and can be the focus of the individualized co-created treatment care plan that was identified as a priority in this study. To facilitate the co-creation of treatment care plans more generally, interdisciplinary gastroenterology providers and persons with IBD could collaborate to create a personalized written care plan[32] template that could be integrated into clinic appointments and individualized based on priorities for care. This document could also include a space for follow-up plans and a written list of resources for individuals with IBD.

Limitations and future research

A convenience sample was used for this study which could have contributed to sampling bias. We experienced attrition from the study by Round 3 which could lead to response bias. The PACIC instrument[9] is not specific to IBD, but general to all chronic health conditions. This factor was mitigated by having all participants provide suggestions for revisions to the statements to be more directed to IBD-specific care. Most participants were diagnosed with IBD before 60 years of age and for the majority of participants, it had been over 6 months since they last saw their IBD provider. Thus, conversations related to the items listed on the PACIC instrument may have occurred months or years earlier and may not have been recalled by participants (ie recall bias). Most participants were female, and responses may not represent the views and priorities of others. By virtue of being involved in the group Delphi process, the pressure to conform to the group responses is a possibility and limitation. However, responses from Rounds 1 and 2 were reported to the participants in a de-identified manner where median rankings (not individual) were provided. Also, participant rankings for Rounds 1 and 3 were completed independently (individually and not in a group setting) to hopefully mitigate pressures to conform to group responses. This study was conducted in a single Western Canadian province. A subsequent multiprovince/national study with a larger sample to indicate the level of importance and determine prioritized statements would be helpful. Obtaining IBD provider rankings on the level of importance of the revised nine statements would enable

comparisons to be made between the difference in expectations between providers and individuals with IBD. It would also be helpful to gather input into how the top prioritized statements could be integrated into practice from a multidisciplinary and patient-centred lens.

Conclusion

With the increasing prevalence of IBD in older adults and the focus on patient-centred care, it is critical to learn more about what matters to older adults in relation to their IBD care. Co-creation of a treatment plan which can be enabled by shared decision-making between the person with IBD and the provider was deemed as a priority to older adults in their IBD-related care. Facilitating collaborative relationships and understanding individual priorities for IBD-related care for older adults has the potential to enhance positive health outcomes and quality of life.

Author Contributions

All authors provided substantial contributions to the study conception and design. Noelle Rohatinsky, Natasha Tooke, and Juan-Nicolás Peña-Sánchez contributed to the data interpretation and drafted the manuscript. All authors revised the manuscript critically for important intellectual content, approved the final version for publication, and agreed to be accountable for all aspects of the work.

Conflict of Interest

N.R. has received speaker fees from Abbvie, Amgen, and CANIBD. S.F. has received consulting fees from Abbvie, Janssen, Takeda, Pendopharm, Pfizer, Amgen, Sandoz, and Eli Lilly. S.F. has received payment from Abbvie, Janssen, Takeda, Pendopharm, Pfizer. S.F. has received support or attending meetings and/or travel from Pfizer. C.R.-C. has received consulting fees from Takeda. C.R.-C. has received support or attending meetings and/or travel from Pfizer. D.M., J.-N.P.-S., N.T., and J.W. declare no conflicts of interest.

Data Availability

The data underlying this article cannot be shared publicly to protect the privacy of individuals who participated in the study.

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