

# The information needs and preferences of persons with longstanding inflammatory bowel disease

Samantha Wong BSc<sup>1</sup>, John R Walker PhD<sup>1,2</sup>, Rachel Carr BA<sup>1</sup>, Lesley A Graff PhD<sup>1,2</sup>, Ian Clara PhD<sup>1</sup>, Stephen Promislow MD<sup>1</sup>, Linda Rogala BN<sup>1,3</sup>, Norine Miller RN<sup>1,3</sup>, Patricia Rawsthorne RN<sup>1,3</sup>, Charles N Bernstein MD<sup>1,3</sup>

S Wong, JR Walker, R Carr, et al. The information needs and preferences of persons with longstanding inflammatory bowel disease. *Can J Gastroenterol* 2012;26(8):525-531.

**BACKGROUND:** Understanding the information needs and preferred vehicles of information delivery to patients with inflammatory bowel disease (IBD) will enhance their care.

**OBJECTIVE:** To survey persons with longstanding IBD as to their information needs and preferred vehicles of information delivery.

**METHODS:** The population-based Manitoba IBD Cohort (n=271, mean disease duration 11 years) was surveyed to assess its information needs across 23 issues, both retrospectively at the time of diagnosis and currently.

**RESULTS:** Most participants (64%) were initially diagnosed by a gastroenterologist, or otherwise by a family physician (19%) or surgeon (12%). Recalling time of diagnosis, at least 80% rated as very important information about common symptoms of IBD, possible complications, long-term prognosis, medication side effects, self management of symptoms and when to involve the doctor, yet only 10% to 36% believed they received the right amount of information about these issues. Dietary guidance was also regarded as important by 80% to 89%, yet only 8% to 16% received the correct amount of information. Regarding current needs, a large proportion believed it would be very helpful to have more information about long-term prognosis (66%) and diet considerations (60% to 68%). The following information sources were regarded as very acceptable: medical specialist (81%); brochure (79%); family doctor (64%); and website (64%), with 51% ranking the medical specialist as the first choice. In a comparison of the responses of this cohort to those of a recently diagnosed sample, there was remarkable consistency in the information needs and most desired sources of information.

**DISCUSSION:** In the present population-based cohort with longstanding disease, dietary information was regarded as the least adequately addressed. There was clear openness to receiving information through other routes than just the medical specialist, suggesting that optimizing brochures and websites would be an important adjunct source of information.

**CONCLUSION:** Approximately 10 years after diagnosis, only a small percentage of persons with IBD believed they received the correct amount of information about the issues they regarded as most important to have discussed at diagnosis.

**Key Words:** Crohn disease; Cohort study; Inflammatory bowel disease; Patient knowledge; Population based; Ulcerative colitis

Optimal management of chronic disease involves a partnership between the patient and physician. This relationship aims to facilitate the involvement of the patient in their own care. Good collaboration is associated with better treatment adherence and improved general

Les besoins et les préférences en matière d'information des personnes ayant une inflammatoire de l'intestin de longue date

**HISTORIQUE :** Le fait de comprendre les besoins d'information et les voies de transmission de l'information favorisées par les patients atteints d'une maladie inflammatoire de l'intestin (MII) permettra d'améliorer leurs soins.

**OBJECTIF :** Faire un sondage auprès de personnes atteintes d'une MII de longue date au sujet de leurs besoins d'information et des voies de transmission de l'information qu'elles favorisent.

**MÉTHODOLOGIE :** Les chercheurs ont sondé la cohorte de MII du Manitoba en population (n=271, durée moyenne de la maladie de 11 ans) pour évaluer ses besoins d'information au sujet de 23 sujets, tant sur le plan rétrospectif au diagnostic qu'au moment du sondage.

**RÉSULTATS :** La plupart des participants avaient d'abord été diagnostiqués par un gastroentérologue (64 %) ou par un médecin de famille (19 %) ou un chirurgien (12 %). Lorsqu'ils se rappelaient leur diagnostic, au moins 80 % trouvaient très important de recevoir de l'information sur les symptômes courants des MII, les complications possibles, le pronostic à long terme, les effets secondaires des médicaments, la prise en charge personnelle des symptômes et les moments de consulter le médecin, mais seulement 10 % à 36 % trouvaient qu'ils avaient reçu assez d'information à ces sujets. De 80 % à 89 % trouvaient également les conseils diététiques importants, mais seulement 8 % à 16 % avaient reçu la bonne quantité d'information. Pour ce qui est des besoins courants, une forte proportion trouvait qu'il serait très utile d'avoir plus d'information sur le pronostic à long terme (66 %) et les questions relatives au régime (60 % à 68 %). Les sources d'information suivantes étaient considérées comme très acceptables : médecin spécialiste (81 %), dépliant (79 %), médecin de famille (64 %) et site Web (64 %), même si 51 % classaient le médecin spécialiste comme leur premier choix. Les réponses de cette cohorte par rapport à celles d'un échantillon récemment diagnostiqué étaient remarquablement semblables en matière de besoins d'information et de sources d'information favorisées.

**EXPOSÉ :** Dans la présente cohorte en population atteinte d'une maladie de longue date, les renseignements relatifs au régime alimentaire étaient considérés comme les moins bien expliqués. Il y avait une réelle ouverture à recevoir de l'information autrement que par le médecin spécialiste, ce qui laisse supposer que l'optimisation des dépliants et des sites Web constituerait une importante source d'information connexe.

**CONCLUSION :** Environ dix ans après le diagnostic, seul un petit pourcentage de personnes atteintes d'une MII considéreraient avoir reçu la bonne quantité d'information sur les sujets qu'elles jugeaient les plus importants à aborder au diagnostic.

health (1,2). An important aspect of this partnership is the exchange of information concerning the disease and its management (3).

Studies of the information preferences and needs of patients have generally found that patients receive less information than they prefer

<sup>1</sup>IBD Clinical and Research Centre; <sup>2</sup>Department of Clinical Health Psychology; <sup>3</sup>Department of Internal Medicine, University of Manitoba, Winnipeg, Manitoba

Correspondence: Dr Charles N Bernstein, University of Manitoba, 804F-715 McDermot Avenue, Winnipeg, Manitoba R3E 3P4.

Telephone 204-789-3369, fax 204-789-3972, e-mail cbernst@cc.umanitoba.ca

Received for publication October 13, 2011. Accepted November 28, 2011

(4-7). Information regarding medications available to the public, for example, can be difficult to understand (8). A recent study by our group (9), which involved 74 patients diagnosed with IBD within three to 24 months, found that 24% were dissatisfied with the information they received close to the time of diagnosis (ie, within two months), 31% were moderately satisfied and only 45% were very satisfied. When their information needs were explored in more detail, however, patients reported that there were many aspects of information about the disease, its treatment and self-management that they considered to be important for which they had received little or no information.

The aim of the present study was to identify the information needs and preferences of persons with longstanding IBD, considering both their needs at the time of diagnosis as well as what was most relevant to them currently after several years living with the disease. We surveyed participants in a population-based IBD cohort who, on average, had the disease for a decade (hereafter referred to as 'the Cohort') (10). The advantage of the population-based sample rather than a clinical convenience sample is that it includes a broader range of patient experience, involving those who may not be seeking treatment or currently involved with treatment. This is especially relevant because treatment-seeking samples often have different characteristics than individuals with chronic disease in the community. The Cohort included IBD participants with active and inactive disease, as well as some receiving treatment and others not. Furthermore, we aimed to contrast the information needs and preferences of those with longstanding disease to a sample of recently diagnosed patients who had been previously described by our group (9).

## METHODS

### Participants

The Manitoba IBD Cohort Study was initiated in 2002, with participating individuals 18 years of age or older and diagnosed with IBD within the previous seven years. They were recruited from a validated population-based research registry that has been previously described (11). The registry identifies and recruits participants based on an administrative definition of IBD from the comprehensive health data base of Manitoba Health, the single insurer that provides health care to all residents of the province.

Of those eligible (ie, all those with IBD in the province), slightly more than one-half participated in the registry. The Cohort study was approved by the University of Manitoba Health Research Ethics Board (Winnipeg, Manitoba) and participants provided written informed consent.

At the time of the Cohort study recruitment, there were 3192 participants in the research registry, of which 606 were eligible for the present study, given the age and recent disease onset criteria. Approximately 17% could not be reached and 14% directly declined to participate. Complete data were obtained in the first contact from 388 of those enrolled, and they have subsequently served as the Cohort, described elsewhere in detail (10). To assess representativeness, cohort participants were compared with all other IBD cases diagnosed in the same time period using a comprehensive validated data set that includes all those in the province with IBD (the University of Manitoba IBD Epidemiology Database). There were no significant differences with respect to standard demographic comparisons including mean age, age distribution, sex distribution, urban versus rural residence and mean duration of disease, suggesting excellent representativeness (12).

Data regarding information needs and preferences were collected 72 months after entry into the longitudinal study, at which point there were 271 individuals with diagnostic and current disease activity information actively participating in the Cohort.

### Measures

**Participant demographics and disease information:** Demographic and disease information was collected regularly from participants in the

Cohort study. Disease diagnosis was self-reported and subsequently confirmed by chart review. For analysis, patients with ulcerative proctitis were included in the ulcerative colitis (UC) group. To assess disease status, participants completed the Manitoba IBD Index (MIBDI). The MIBDI is a single-item rating scale validated to characterize disease activity, based on symptom frequency over the previous six months, and is particularly applicable for longitudinal studies involving multiple measurement periods (13). Those who rated their symptoms as constantly active, often active, sometimes active or occasionally active (one to two days per month) were categorized as having active disease. Those reporting their symptoms as occurring rarely to never over the previous six months were categorized as having inactive disease, based on the MIBDI. Disease-related quality of life was evaluated using the Inflammatory Bowel Disease Questionnaire (IBDQ). The IBDQ is a well-validated, 32-item questionnaire designed to assess health-related quality of life (14). Scores are strongly correlated with disease activity. Higher scores reflect better quality of life, and a cutoff of 170 has been previously identified (14).

### Information needs survey for IBD

The team developed a self-report survey, with questions based on previous research that focussed on information needs and sources when patients are considering treatment for a wide range of conditions (4-6). Domains assessed in previous studies that were adapted for the present survey included satisfaction with information provided, identification of types of relevant information sources, preferences for information sources for new treatments and importance ratings for specific types of information. Item content that was specific to IBD, based on experience in specialty gastroenterology clinics regarding common patient queries about their disease, was developed. These items cover three areas: clinical information concerning IBD (seven items), medical treatment of IBD (seven items) and self-management of IBD (nine items). All of these items were rated as important in the previous study of recently diagnosed IBD patients in a clinical sample (9) and, thus, were kept for the current community-based IBD sample.

The survey preamble stated: "We are interested in learning what information would be helpful when someone finds out they have inflammatory bowel disease and what information would be helpful in managing the disease. We will be asking questions about your experiences when you first found out you had IBD and then about the type of information that would be useful to you in the future". In Part I of the survey, respondents were directed to recall the time period when they were diagnosed with IBD. The first question asked who initially provided the IBD diagnosis (from a list of health care providers). The second question asked about satisfaction with information: "Thinking of the information you received within the first two months after you were given your diagnosis, how satisfied were you with the information you obtained about IBD and the treatment of IBD?" Rating was performed Likert scale from 0 to 8, with higher scores reflecting greater satisfaction. The next series of questions asked about the amount of information obtained from various sources: "Thinking more specifically of the information you received within the two months after you were given your diagnosis, how much information did you obtain about IBD and its treatment from the following sources?" A list of information sources, including health care providers and community sources, was provided. The next group of questions asked about satisfaction with the amount of information obtained relating to 23 IBD disease and management topics: "Thinking more specifically of the information you received within the two months after you were given your diagnosis, how much information did you obtain about the following topics?" Participants rated the amount of information they received about each topic using a six-point scale, ranging from 'no information' to 'far too much information'. Importance of each IBD topic was assessed by asking: "If you had a close family member or friend who just found out that they had IBD, how important do you think it would be for them to receive information in the following areas in the first two months after they had gotten their diagnosis?". Ratings of importance

were collected on a Likert scale from 0 to 8, with higher values meaning greater importance.

In Part II of the survey, respondents were asked to consider their current information needs. They were asked to provide ratings of helpfulness of more information, based on the 0 to 8 scale (with higher scores meaning greater helpfulness), for each of the 23 IBD disease and management items. The following instructions were used: "Now we would like to ask you the same questions thinking about information that would be helpful to you right now. Many people with IBD pick up a good deal of information about the disease over time. Considering the information you already have about IBD, how helpful would it be for you to have more information in the following areas?" To assess future information needs respondents were asked "If information became available about a new medication treatment for IBD and you were having active symptoms, how important would it be for you to have the following information? This information might influence whether you would want to consider the new treatment at some point".

Finally, in Part III, acceptability and preferences of different methods of communication were assessed. Respondents rated a variety of methods of communication using a nine-level response format ranging from 'not at all acceptable' (0) to 'very acceptable' (8) in response to the following instructions: information about new treatments can be provided in a number of ways. How acceptable would the following ways of providing information be for you if there was a lot of information to consider about a new treatment? Following these questions respondents were asked to rank their first five choices (from one to five) from the list of nine communication methods.

## RESULTS

The demographic and disease characteristics of participants are described in Table 1. Sixty-four per cent of the participants were diagnosed by a gastroenterologist, while 19% and 12% were diagnosed by a family doctor or surgeon, respectively. Using the MIBDI classification of disease activity, 52% of the participants were characterized as having active disease during the previous six months, and 33% scored below the IBDQ threshold (ie, <170), suggesting poor quality of life. There were fewer males than females (39% versus 61%), and mean age for the sample was 47 years. Most of the participants were married (68%) and working outside the home (64%). Two-thirds of the participants had some postsecondary education or training.

### Information needs at time of diagnosis and currently

In describing their overall satisfaction with the amount of information they received during the first two months after diagnosis, 38% reported feeling dissatisfied with the information they were given at the time of their diagnosis, while 62% reported that they were moderately to very satisfied. Participants reported on the amount of information they received from a variety of possible sources during the first two months after diagnosis, with only a modest proportion indicating they received the 'right amount' of information. The sources most frequently listed as providing the needed amount of information were a gastroenterologist (36%), a website about IBD (19%), materials from the Crohn's and Colitis Foundation (16%), and a family doctor (14%). The percentage of participants who indicated that they received a moderate amount of information was also relatively low, with the most frequent sources being a gastroenterologist (30%), brochures at a medical appointment (20%), a family doctor (18%), and materials from the Crohn's and Colitis Foundation (18%). A majority of the participants (57% to 90%) believed they received little to no information from most sources, while a very small percentage (0% to 3%) believed they received too much information.

Tables 2, 3 and 4 compare the amount of the information received on common clinical content areas for chronic disease and the importance of receiving that information early after diagnosis (ie, within the first two months). The tables also include responses on the current helpfulness of information in these areas, an average of 11 years after

**TABLE 1**  
Demographic and disease characteristics of study participants

	Total (n=271)
Male/female, n/n	106/165
Age, years, mean $\pm$ SD	46.5 $\pm$ 14.5
Marital status	
Married/common law	68.3
Separated/divorced/widowed	14
Single, never married	17.7
Occupational status (30-month data)	
Work (full-time and part-time)	63.8
School	5.5
Homemaker/retired	18.5
Disabled	4.8
Other	3.4
Level of education	
No postsecondary	35.8
Trades/nonuniversity certificate or diploma/below bachelor degree	36.4
Bachelor degree	13.6
Above bachelor degree	11.2
Disease characteristics	
CD/UC/IBD-type unspecified, n/n/n	132/138/1
Age at diagnosis, years, mean $\pm$ SD	35.7 $\pm$ 14.4
Age at onset of symptoms, years, mean $\pm$ SD	31.0 $\pm$ 14.9
Active disease (MIBDI)	52.1
Quality of Life (IBDQ), mean score $\pm$ SD	176.7 $\pm$ 29.3
Poor quality of life, IBDQ score <170	32.5
Received initial diagnosis from:	
Family doctor	19
Gastroenterologist	64
Nurse	1
Surgeon	12
Parent	0
Someone else/do not know	4

Data presented as % unless otherwise indicated. CD Crohn disease; IBD Inflammatory bowel disease; IBDQ Inflammatory Bowel Disease Questionnaire; MIBDI Manitoba IBD Index; UC Ulcerative colitis

diagnosis. Table 2 displays ratings of clinically related IBD information, such as common symptoms, fertility issues and cancer risk. Most participants believed that information on these topics is very important in the first two months after diagnosis, but only small proportions indicated that they received the needed amount of information in each area. There was less interest in these topics currently than there was early after diagnosis. Nonetheless, information regarding several of these clinical topics was currently considered to be helpful by a large proportion of respondents. The content areas that were viewed as most helpful currently in dealing with IBD included long-term prognosis, causes of IBD and complications of IBD.

Table 3 presents ratings of information related to medical treatment of IBD. The vast majority of participants (80% to 90%) rated these topics as very important in the first two months of diagnosis. However, only a small proportion believed that they received the right amount of information, particularly in areas such as medication treatment, possible side effects, IBD-related pain management, management of other symptoms and when to contact the doctor. The topic that the largest proportion of respondents (32%) believed that they had received the right amount of information about was medication treatments for IBD; this seems very low given the importance of this issue. Considering current information needs, approximately one-half of the respondents (44% to 61%) indicated that it would be very helpful to have information on each of these topics.

**TABLE 2**  
**Clinically related inflammatory bowel disease (IBD) information: Ratings of the amount of information received and the importance of information within two months of diagnosis and the helpfulness of information currently**

Information topic	Rating of amount of information received within first 2 months			Rating of information topics			
	None/a little	Right amount	Mean rating (95% CI)	Within first 2 months		Currently	
				Rated as very important	Mean rating (95% CI)	Rated as very helpful	Mean rating (95% CI)
Common symptoms of IBD	28	36	2.2 (2.06–2.35)	85	7.1 (6.92–7.27)	33	3.8 (3.48–4.16)
Complications that may arise from IBD	42	26	2.0 (1.85–2.18)	80	6.8 (6.65–7.03)	50	5.2 (4.88–5.49)
What is known (or not known) about the causes of IBD	49	22	1.8 (1.61–1.97)	68	6.3 (6.11–6.57)	55	5.5 (5.23–5.82)
Long-term prognosis/ outcome of IBD	69	11	1.3 (1.15–1.54)	82	6.8 (6.61–7.00)	66	6.2 (5.89–6.41)
Risk of developing cancer	73	8	1.2 (1.04–1.44)	78	6.7 (6.46–6.89)	47	4.7 (4.38–5.05)
How IBD or the medications used may affect fertility	84	5	0.8 (0.60–1.05)	70	6.4 (6.14–6.63)	34	3.7 (3.36–4.12)
The risk that children of persons with IBD have of developing IBD	82	4	1.00 (0.73–1.17)	64	6.0 (5.78–6.28)	41	4.3 (3.97–4.67)

Data presented as % unless otherwise indicated. Participants rated how much information they received in each of these areas on a 7-point rating scale with the following anchors: 0–1 (none/a little); 2 (a moderate amount); 3 (just the right amount); 4–5 (too much/way too much); and 6 (do not recall). Very few respondents indicated too much information (5% at most in any area) or do not recall (5% to 10%); therefore, these scores were not included in the calculation of the mean rating. Each potential information topic was also rated on a 9-point rating scale with the anchors: 0–2 (not important); 3–5 (moderately important); and 6–8 (very important). Rating of helpfulness currently was on a similar 9-point scale

**TABLE 3**  
**Medical treatment of inflammatory bowel disease (IBD): Ratings of the amount of information received and the importance of information within two months of diagnosis and the helpfulness of information currently**

Information topic	Rating of amount of information received within first 2 months			Rating of information topics			
	None/a little	Right amount	Mean rating (95% CI)	Within first 2 months		Currently	
				Rated as very important	Mean rating (95% CI)	Rated as very helpful	Mean rating (95% CI)
Medication treatments for IBD	32	32	2.1 (1.96–2.24)	89	7.3 (7.13–7.43)	56	5.5 (5.22–5.83)
Possible side effects of medication treatments	50	21	1.8 (1.59–1.95)	86	7.2 (6.98–7.33)	61	5.8 (5.51–6.09)
Surgical treatments that may be required for IBD	51	20	1.8 (1.60–2.00)	70	6.4 (6.13–6.57)	44	4.7 (4.40–5.07)
How to manage pain related to IBD	66	10	1.6 (1.35–1.80)	88	7.2 (7.05–7.36)	59	5.6 (5.25–5.85)
How to manage other symptoms of IBD	64	10	1.6 (1.35–1.79)	86	7.1 (6.97–7.30)	61	5.8 (5.47–6.04)
How to adjust medications when symptoms cause problems	67	15	1.3 (1.10–1.52)	84	7.0 (6.82–7.18)	57	5.4 (5.06–5.70)
When to contact your doctor	52	25	1.7 (1.54–1.94)	89	7.3 (7.13–7.42)	49	4.9 (4.51–5.21)

Data presented as % unless otherwise indicated. Participants rated how much information they received in each of these areas on a 7-point rating scale with the following anchors: 0–1 (none/a little); 2 (a moderate amount); 3 (just the right amount); 4–5 (too much/way too much); and 6 (do not recall). Very few respondents indicated too much information (5% at most in any area) or do not recall (5% to 10%); therefore, these scores were not included in the calculation of the mean rating. Each potential information topic was also rated on a 9-point rating scale with the anchors 0–2 (not important), 3–5 (moderately important) and 6–8 (very important). Rating of helpfulness currently was on a similar 9-point scale

**TABLE 4**  
**Self-management of inflammatory bowel disease (IBD): Ratings of the amount of information received and the importance of information within two months of diagnosis and the helpfulness of information currently**

Information topic	Rating of amount of information received within first 2 months			Rating of information topics			
	None/a little	Right amount	Mean rating (95% CI)	Within First 2 months		Currently	
				Rated as very important	Mean rating (95% CI)	Rated as very helpful	Mean rating (95% CI)
Changes to diet that may be helpful when IBD is active	56	16	1.5 (1.33–1.70)	89	7.3 (7.16–7.46)	68	6.1 (5.81–6.38)
Changes to diet that may be helpful when IBD is inactive	64	12	1.3 (1.11–1.49)	83	7.0 (6.74–7.12)	64	5.7 (5.40–6.04)
What foods offer the best nutritional value	71	9	1.2 (0.99–1.36)	80	6.8 (6.62–6.99)	64	5.9 (5.62–6.20)
What nutritional deficiencies you may be at risk for	76	8	1.1 (0.90–1.25)	83	7.0 (6.78–7.15)	61	5.7 (5.43–6.02)
When to use nutritional supplements	75	8	1.1 (0.91–1.31)	74	6.5 (6.27–6.69)	29	3.5 (3.14–3.85)
Informing family members about IBD	79	6	1.0 (0.80–1.24)	59	5.8 (5.49–6.00)	52	5.1 (4.75–5.44)
How to manage time away from work/school	85	4	0.8 (0.58–1.01)	64	6.2 (5.93–6.40)	32	3.7 (3.31–4.05)
Insurance that may be available if sick days run out	87	3	0.7 (0.45–0.86)	71	6.4 (6.16–6.65)	45	4.4 (3.98–4.75)
Sources of support in coping with IBD	76	7	1.1 (0.88–1.26)	72	6.4 (6.19–6.63)	68	5.7 (5.37–5.99)

Data presented as % unless otherwise indicated. Participants rated how much information they received in each of these areas on a 7-point rating scale with the following anchors: 0–1 (none/a little); 2 (a moderate amount); 3 (just the right amount); 4–5 (too much/way too much); and 6 (do not recall). Very few respondents indicated too much information (5% at most in any area) or do not recall (5% to 10%); therefore, these scores were not included in the calculation of the mean rating. Each potential information topic was also rated on a 9-point rating scale with the anchors 0–2 (not important), 3–5 (moderately important) and 6–8 (very important). Rating of helpfulness currently was on a similar 9-point scale

**TABLE 5**  
Ratings of importance of obtaining information concerning new treatments for inflammatory bowel disease (IBD)

Topic	Rated as very important, %	Mean rating (95% CI)
A) The effectiveness of new medication	86	7.1 (6.92–7.29)
B) The effectiveness of the new medication compared with previously available treatments	87	7.1 (6.90–7.28)
C) How the medication works	80	6.8 (6.61–7.03)
D) When and how you take the new medication	81	6.9 (6.70–7.12)
E) The cost of the medication	73	6.4 (6.18–6.69)
F) Common side effects of the medication	88	7.2 (7.00–7.33)
G) Uncommon or rare side effects of the medication	81	6.8 (6.59–7.00)
H) How long it takes before the medication reduces IBD symptoms	87	7.0 (6.82–7.19)
I) How long you have to take the medication for	86	6.9 (6.73–7.10)
J) What happens when the medication is discontinued	82	6.9 (6.68–7.08)
K) What medication your doctor would recommend for your situation	88	7.1 (6.96–7.31)
L) Participating in a clinical trial using an investigational drug to find a new treatment for IBD	65	5.9 (5.63–6.21)
M) Participating in a clinical trial where you may be assigned to receive either the study drug or placebo	55	5.4 (5.07–5.71)
N) Participating in a clinical trial that would take more than one year to complete	58	5.5 (5.14–5.77)
O) Participating in a clinical trial as an option provided to me by my physician	61	5.7 (5.40–5.99)

Participants were asked to rate the importance of information about a new treatment if they were experiencing active symptoms. Each potential information topic was also rated on a 9-point rating scale with the following anchors: 0–2 (not important); 3–5 (moderately important); and 6–8 (very important)

Table 4 describes information needs related to self-management of IBD. Most respondents rated most of the topics in this section as very important at the time of diagnosis, including diet changes with active or inactive IBD (89% and 83%, respectively), risks of nutritional deficiencies (83%) and what foods offer the best nutritional value (80%). Again, while the topic areas were regarded as highly important, very few participants believed they had received the needed (ie, 'right amount') of information. There was continued interest in areas related to nutrition currently in their disease experience, but fewer believed that information on when to use nutritional supplements (29%) and how to manage help away from work or school (32%) would be very helpful.

#### Future information needs

Participants were asked about the importance of receiving various aspects of information about any new medication that might become available. As shown in Table 5, the majority of participants rated all of the information topics as very important (80% indicating this for most topics from A to K). However, fewer (55% to 65%) endorsed information about clinical trials (topics L to O) as 'very important'.

Also explored was the relationship between demographic and disease characteristics with information preferences. To consider information preferences currently, the average rating of the importance of information about a new treatment of IBD (items A to K in Table 5) were calculated. A multiple regression analysis was conducted with three demographic variables (sex, age and education) and two disease variables (diagnosis and disease activity) as predictors of importance ratings. Results of the analysis are presented in Table 6. The demographic characteristics accounted for very little variance in ratings of importance ( $R=0.157$ ,  $R^2=0.025$ ). Sex was the variable most strongly related to ratings of information importance, with women making slightly higher ratings of information importance than men.

#### Sources of information

Table 7 presents ratings of the acceptability of various sources of information and ranking of these sources in the context of considering a new medication for IBD. Participants indicated that a wide range of information sources would be very acceptable, with the highest ratings for medical specialists, brochures and booklets, the family doctor and a recommended website. With forced choice ranking, as a first choice, 51% identified a medical specialist, 17% a brochure, 13% their family doctor and 12% a recommended website. For the second choice, 35% indicated their family doctor, 19% a medical specialist, 16% a brochure and 12% recommended a website.

**TABLE 6**  
Multiple regression analysis with demographic and disease characteristics as predictors of ratings of importance of information about a new treatment

Variable	b	beta	t	P
Constant	6.17	–	11.04	<0.0001
Sex	0.330	0.122	1.90	0.059
Age	0.143	0.054	0.82	0.408
Education	0.003	0.001	0.02	0.985
CD/UC	0.161	0.061	0.93	0.355
Disease activity	–0.136	–0.052	–0.79	0.430

CD Crohn disease; UC Ulcerative colitis

#### Comparisons between the Cohort and recently diagnosed samples

In comparing the findings from the community-based IBD Cohort sample who have had longstanding disease with those from the previous study with recently diagnosed clinic patients (9), it is important to be aware of similarities and differences between the samples. The Cohort and clinic samples had similar proportions of IBD subtypes (approximately one-half each of CD and UC in each sample), mean age at diagnosis (35.7 years and 36.4 years, respectively) and proportion with no postsecondary education (36% and 39%, respectively). However, the Cohort sample was older (mean age 46.5 versus 37.8 years), had fewer with active disease (52% versus 68%), fewer working outside the home (64% versus 76%), and higher proportions of women (61% versus 53%) and married persons (68% versus 55%). Differences in the background characteristics, such as marital status and work activity, are likely related to the age and sex differences between the samples (eg, younger people are less likely to be married, older people are less likely to be working, more men work outside of the home). Nonetheless, despite these differences, the two groups were remarkably similar in their responses to the information needs survey. Table 8 highlights some of these comparisons.

Dissatisfaction with the information received within two months of diagnosis was higher in the Cohort sample than in the recently diagnosed sample (38% versus 24%), raising the possibility that there may have been an improvement in disease information provision or accessibility at diagnosis in recent years. In terms of sources of information within the first two months of diagnosis, a similar proportion of respondents in both the Cohort sample and the recently diagnosed sample (36% for both) indicated that they received the correct

**TABLE 7**  
**Preferences for source of information concerning a new treatment**

	Rated as very acceptable	Mean rating (95% CI)	Ranked as first choice
Brochure or booklet	79	6.7 (6.52–6.95)	17
Discussion with your family doctor	64	6.0 (5.79–6.27)	13
Discussion with a medical specialist	81	6.8 (6.62–6.99)	51
Video recording	52	5.4 (5.16–5.72)	4
A website recommended by your health care provider	64	5.9 (5.59–6.15)	12
Information provided by a support group such as the Crohn's and Colitis Foundation	60	5.8 (5.49–6.01)	1
Discussion with a nurse	56	5.6 (5.32–5.82)	2
Discussion with a pharmacist	41	4.8 (4.53–5.07)	–
Discussion with a family member	22	3.5 (3.20–3.77)	–

Data presented as % unless otherwise indicated. Each source of information was rated on a 9-point rating scale with the following anchors: 0–2 (not at all acceptable); 3–5 (moderately acceptable); and 6–8 (very acceptable). Respondents then ranked their most preferred source of information by indicating the first, second, third, fourth and fifth ranked choice. Only information about the first ranked choice is shown

amount of information from a gastroenterologist. However, fewer in the Cohort sample reported that they received the correct amount of information from the Internet (19% versus 38%). This greater use of the Internet by the recently diagnosed sample is not surprising given the much increased use of the Internet over the past 10 years (15) and the much wider range of information available there (16–19).

Respondents in both samples believed it was very important to receive information on a wide range of topics within two months of diagnosis. Similar proportions received little or no information on most IBD-related topics in the Cohort sample and the recent diagnosis sample (Table 8), despite being diagnosed a decade apart. The topics identified as having the highest importance were also quite similar in the Cohort sample and the recent diagnosis sample as were their views on clinical trials information (data not shown).

With regard to acceptability of information from a wide range of sources, the samples were also very similar in their ratings. The Internet (ie, a recommended website), which is now a major source of information, was rated as very acceptable by both the Cohort sample and the recently diagnosed sample (64% versus 58%). Both samples also rated more traditional modalities of information, such as a brochure format, as very acceptable (79% and 73%). A slightly lower proportion of participants in the Cohort (51%) ranked a medical specialist as the first choice for information source compared with the newly diagnosed sample (68%).

## DISCUSSION

The aim of the present study was to explore the information needs and preferences of respondents recruited from a population-based cohort of persons living with IBD for several years, emphasizing both their needs at diagnosis as well as currently. The comparison of the community IBD cohort information experiences with a clinical sample of recently diagnosed IBD patients (9) also served to establish generalizability and durability of information needs.

When Cohort participants were asked about their overall satisfaction with the amount of information they received during the first two months after diagnosis, 62% reported that they were moderately to very satisfied. Probing further about the information received at that time, however, we found that many respondents recalled that they received little or no information on specific topics around clinical information concerning IBD, medical treatment of IBD and self-management of IBD. All of these topics were considered to be very important near

**TABLE 8**  
**Comparison of selected findings from the recently diagnosed sample\* compared with the Cohort sample**

	Sample	
	Recently diagnosed (n=74)	Cohort (n=271)
Source providing the 'right' amount of information within two months of diagnosis		
Gastroenterologist	36	36
Internet	38	19
Proportion of respondents who received 'little or no information' on important topics		
Common symptoms of IBD	27	28
Complications	36	42
Causes of IBD	50	49
Prognosis	78	69
Risk of developing cancer	77	73
How medications may affect fertility	86	84
Risk of their children developing IBD	82	82
Medications	32	32

Data presented as %. \*The data from the recently diagnosed sample (surveyed within two to 24 months of diagnosis) are reported in full in reference 9. IBD Inflammatory bowel disease

the time of diagnosis by a large majority of the respondents. While participants may have accumulated considerable information concerning IBD in the years since diagnosis, they indicated that even now it would be very helpful to receive information in most of these topic areas. While respondents particularly valued information from a medical specialist, there was also openness to obtaining relevant disease-related information from a wide variety of other information sources, such as paper-based brochures and the Internet.

In comparing the findings between the Cohort sample and the recently diagnosed sample, the information needs and preferences were remarkably similar. This was in spite of some differences in age, sex distribution, employment status and disease duration between the samples, as well as the decade in which the diagnosis was delivered. These findings suggest some consistency or durability in the type of information that is regarded as helpful. Furthermore, demographic variables did not predict preferences, for instance, on information about new treatments, although women rated the importance of information about new treatments slightly higher than men.

It can be challenging to provide such a wide range of information to patients in the time available during standard medical consultations. It is also difficult for patients to remember information communicated orally (20). An effective approach is to supplement information communicated in consultations with written information (21). Written information may be provided in the form of traditional brochures (possibly downloaded by the provider from the Internet) or through recommended websites. Internet information has the advantage that it can be tailored to the needs of the individual so that the person can review information in more or less detail and explore topics that are of particular interest. The public currently uses the Internet extensively as a source of health information (22,23), and information is always available and conveniently accessed. In particular, persons with chronic health conditions use the Internet (and other sources) to obtain information independent of medical consultations (24).

People may be most interested in receiving information when they are at the point of making decisions about management or at points in which they are having difficulty with symptoms. A range of information is particularly valued by patients shortly after their diagnosis. Previous research by our group suggests that the IBD information currently available on the Internet does not adequately address many of

the topics identified as important by the respondents in the present study (25). A relevant goal for patient support should be to improve the breadth and depth of information available on the Internet.

Another challenge is to develop high-quality, evidence-based information on the many topics that are of interest to persons with IBD. Not all experts agree on the information that would address each of the topics and, in many of these areas, especially self-management, there is limited information available. Key processes to address this challenge are: first, to determine what information persons with IBD need and want; second, to develop educational material based on available evidence; third, to arrange for review of educational material by experts and IBD patients; and, finally, to field test materials by users and practitioners (26). The present study contributes to the important first step of identifying relevant domains and information gaps for IBD patients.

The present study has several limitations. We did not assess knowledge about the disease or its management or perceptions of knowledge about the disease (27). Rather, we assessed the perceived utility of information on a wide range of topics. Some persons with IBD may be quite knowledgeable but still have an interest in receiving more information. Another limitation was that the Cohort sample had an extensive recall period regarding their needed information at the time of diagnosis. However, it is interesting to note that the information needs and experiences were very similar to those of a recently diagnosed clinical sample in spite of differences in time since diagnosis. A strength of the study was that the Cohort sample was recruited from a population-based registry. Finally, applying the same survey to experienced patients that was used for 'inexperienced' IBD patients allowed us to contrast information needs at different times in the disease process and to determine that the information needs are consistent.

---

**DISCLOSURES:** Dr Charles Bernstein is supported in part by the Bingham Chair in Gastroenterology. In the past year, Dr Bernstein has served on the advisory boards for Abbott Canada, Astra Zeneca Canada, Janssen Canada and Shire Canada and has received research grant support from Abbott Canada and Prometheus Laboratories and educational grant support from Aptalis. There are no other conflicts of interest to declare.

---

## REFERENCES

- Lipkus IM. Numeric, verbal, and visual formats of conveying health risks: Suggested best practices and future recommendations. *Med Decis Making* 2007;27:696-713.
- Kane S. Information Needs and preferences in IBD (IBD self-management: The AGA guide to Crohn's disease and ulcerative colitis). *Inflamm Bowel Dis* 2011;17:E102.
- Schwappach DL, Mülders V, Simic D, Wilm S, Thürmann PA. Is less more? Patients' preferences for drug information leaflets. *Pharmacoepidemiol Drug Saf* 2011;20:987-95.
- Dickinson D, Raynor DK. What information do patients need about medicines? Ask the patients – they may want to know more than you think. *BMJ* 2003;327:861.
- Nair K, Dolovich L, Cassels A, et al. What patients want to know about their medications. Focus group study of patient and clinician perspectives. *Can Fam Physician* 2002;48:104-10.
- Raynor DK, Blenkinsopp A, Knapp P, et al. A systematic review of quantitative and qualitative research on the role and effectiveness of written information available to patients about individual medicines. *Health Technol Assess* 2007;11:iii,1-160.
- Carrigan N, Raynor DK, Knapp P. Adequacy of patient information on adverse effects: An assessment of patient information leaflets in the UK. *Drug Saf* 2008;31:305-12.
- Mansfield JC, Tanner AR, Bramble MG. Information for patients about inflammatory bowel disease. *J R Coll Phys Lond* 1997;31:184-7.
- Bernstein K, Promislow S, Carr R, Rawsthorne P, Walker JR, Bernstein CN. The information needs and preferences of recently diagnosed patients with IBD. *Inflamm Bowel Dis* 2011;17:590-8.
- Graff LA, Walker JR, Lix L, et al. The relationship of inflammatory bowel disease type and activity to psychological functioning and quality of life. *Clin Gastro Hepatol* 2006;4:1491-501.
- Bernstein CN, Blanchard JF, Rawsthorne P, et al. The epidemiology of Crohn's disease and ulcerative colitis in a central Canadian province: A population-based study. *Am J Epidemiol* 1999;149:916-24.
- Longobardi T, Walker JR, Graff LA, Bernstein CN. Health service utilization in IBD: Comparison of self-report and administrative data. *BMC Health Serv Res* 2011;11:137.
- Clara I, Lix LM, Walker JR, et al. The Manitoba IBD Index: Evidence for a new and simple indicator of IBD activity. *Am J Gastroenterol* 2009;104:1754-63.
- Irvine EJ, Feagan B, Rochon J, et al; for the Canadian Crohn's Relapse Prevention Trial. Quality of Life: A valid and reliable measure of therapeutic efficacy in the treatment of inflammatory bowel disease. *Gastroenterology* 1994;106:287-96.
- Fox S, Purcell K. Chronic Disease and the Internet. <[www.pewinternet.org/Reports/2010/Chronic-Disease.aspx](http://www.pewinternet.org/Reports/2010/Chronic-Disease.aspx)> (Accessed June 20, 2011).
- Atkinson NL, Saperstein SL, Pleis J. Using the internet for health-related activities: Findings from a national probability sample. *J Med Internet Res* 2009;11:e4.
- Miller EA, West DM, Wasserman M. Health information websites: Characteristics of US users by race and ethnicity. *J Telemed Telecare* 2007;13:298-302.
- Rice RE. Influences, usage, and outcomes of Internet health information searching: Multivariate results from the Pew surveys. *Int J Med Inform* 2006;75:8-28.
- Choi N. Relationship between health service use and health information technology use among older adults: Analysis of the US National Health Interview Survey. *J Med Internet Res* 2011 20;13:e33.
- Kessels, RPC. Patients' memory for medical information. *J Royal Soc Med* 2003;96:219-22.
- Watson PW, McKinstry B. A systematic review of interventions to improve recall of medical advice in healthcare consultations. *J Royal Soc Med* 2009;102:235-43.
- Baker L, Wagner TH, Singer S, Bundorf MK. Use of the Internet and e-mail for health care information: Results from a national survey. *JAMA* 2003;289:2400-406.
- Beckjord EB, Finney Rutten LJ, Squiers L, et al. Use of the internet to communicate with health care providers in the United States: Estimates from the 2003 and 2005 Health Information National Trends Surveys (HINTS). *J Med Internet Res* 2007;9:e20.
- Bundorf MK, Wagner TH, Singer SJ, Baker LC. Who searches the internet for health information? *Health Serv Res* 2006;41:819-36.
- Promislow S, Walker JR, Taheri M, Bernstein CN. How well does the Internet answer patients' questions about inflammatory bowel disease? *Can J Gastroenterol* 2010;24:671-7.
- Siegel CA. Explaining risks of inflammatory bowel disease therapy to patients. *Aliment Pharmacol Ther* 2011;33:23-32.
- O'Sullivan MA, Mahmud N, Kelleher DP, Lovett E, O'Morain CO. Patient knowledge and educational needs in irritable bowel syndrome. *Eur J Gastroenterol Hepatol* 2000;12:39-43.



**Hindawi**  
Submit your manuscripts at  
<http://www.hindawi.com>

