

The information needs and preferences of persons with longstanding IBD

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Abstract

Background: Understanding the information needs and preferred vehicles of information delivery of patients with IBD will enhance their care.

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

Methods: We surveyed the population-based Manitoba IBD Cohort (n=271) with a mean disease duration of 11 years, to assess their 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 10-36%, felt they received the right amount of information about those issues. Dietary guidance was also seen as important by 80-89%, yet only 8-16% received the right amount of information. Regarding current needs, a large proportion felt it would be very helpful to have more information about long-term prognosis (66%) and diet considerations (60-68%). These information sources were viewed as very acceptable: medical specialist (81%), brochure (79%), family doctor (64%) and website (64%) with 51% ranking the medical specialist as 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 this population-based cohort with longstanding disease, dietary information was seen as 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 the minority of persons with IBD thought they received the right amount of information about the issues they viewed as most important to have discussed at diagnosis.

Introduction

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 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 generally have found that patients receive less information than they prefer (4-7). The information available to the public about medications, for example, can be difficult to understand (8). A recent study by our group (9), involving 74 patients diagnosed with IBD within 3 – 24 months, found that 24% were dissatisfied with the information they received close to the time of diagnosis (i.e., 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 areas of information about the disease, its treatment, and self-management that they considered to be important where they had received little or no information.

The aim of this 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 had the disease for a decade, on average (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 as 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. Further, we aimed to contrast the information needs and preferences of those with more longstanding disease to a sample of recently diagnosed patients that had been previously described by our group (9).

METHODS

Participants

The Manitoba IBD Cohort Study was initiated in 2002, with participating individuals in their 18th year or older and diagnosed with IBD within the previous 7 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 in the province. Of those eligible, that is all those with IBD in the province, just over half participated in the Registry. The Cohort Study was approved by the University of Manitoba Health Research Ethics Board 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 this study, given the age and recent disease onset

criteria. Approximately 17% could not be reached and 14% directly declined to take part. 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 to all other IBD cases diagnosed in the same time period, using a comprehensive validated data set which includes all those in the province with IBD (the University of Manitoba IBD Epidemiology Database). There were no significant differences on standard demographic comparisons including mean age, age distribution, sex distribution, urban vs. rural residence, and mean duration of disease, suggesting excellent representativeness (12).

Data on 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 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 6 months, and is particularly applicable for longitudinal studies with multiple measurement periods (13). Those who rated their

symptoms as constantly active, often active, sometimes active, or occasionally active (1-2 days/month) were categorized as having active disease. Those reporting their symptoms as occurring rarely to never over the previous 6 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 one's 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

Our 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 (4,5,6). Domains assessed in prior studies that were adapted for this 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. We developed item content that was specific to IBD, based on experience in specialty gastroenterology clinics regarding common patient queries about their disease. These items cover three areas: clinical information concerning IBD (7 items), medical treatment of IBD (7 items), and self-management of IBD (9 items). All of these items were rated as important in our 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 on a 0 to 8 Likert scale, 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 6-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 0 to 8 Likert scale, 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 9 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. 64% 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 past 6 months, and 33% scored below the IBDQ threshold (i.e., <170), suggesting poor quality of life. There were fewer males than females (39% vs. 61%), and mean age for the sample was 47 years old. 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 2 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 satisfied to very satisfied. Participants reported on the amount of information they received from a variety of possible sources during the first 2 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 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 (57–90%) felt they received little to no information from most sources, while a very small percentage (0–3%) felt they received too much information.

Tables 2a, 2b, and 2c 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 (i.e., 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 diagnosis. Table 2a displays ratings of clinically-related IBD information, such as common symptoms, fertility issues, and cancer risk. Most participants felt 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 on several of these clinical topics was currently considered to be helpful by 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 2b displays ratings of information related to medical treatment of IBD. The vast majority of participants (80%-90%) rated these topics as very important in the first two months of diagnosis. However, only a small proportion felt 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%) felt that they had received the right amount of information about was medication treatments for IBD, and this seems very low given the importance of this issue. Considering current information needs, almost half the respondents (44 – 61%) indicated that it would be very helpful to have information on each of these topics.

Table 2c 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 seen as highly important, very few participants felt they had received the needed (i.e., ‘right amount’) of information. There was continued interest in areas related to nutrition currently in their disease experience, but fewer felt 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 3, 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 (55-65%) endorsed information about clinical trials (topics L to O) as ‘very important’.

We also explored the relationship of demographic and disease characteristics with information preferences. In order to consider information preferences currently, we calculated the average rating of the importance of information about a new treatment of IBD (items A to K in Table 3). A multiple regression analysis was conducted with three demographic variables (sex, age, education) and two disease variables (diagnosis and disease activity) as predictors of importance ratings. Results of the analysis are shown in Table 4. The demographic characteristics accounted for very little variance in ratings of importance $R = .157$, $R^2 = .025$. Gender was the variable most strongly related to ratings of information importance with females making slightly higher ratings of information importance than males.

Sources of Information

Table 5 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% a recommended website.

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 our 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 (about 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 post-secondary education (36% and 39%). However, the Cohort sample was older (mean age 46.5 vs. 37.8), had fewer with active disease (52% vs. 68%), fewer working outside the home (64% vs. 76%), and higher proportions of females (61% vs. 53%) and married persons (68% vs. 55%). Differences in the background characteristics such as marital status and work activity are likely related to the age and gender differences between the samples (e.g., younger people are less likely to be married, older people are less likely to be working, more males work outside of the home). Nonetheless, despite these differences the two groups were remarkably similar in their responses to the information needs survey. Table 5 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% vs. 24%), raising the possibility that there may be an improvement in disease information provision or accessibility at diagnosis in recent years. In terms of sources of information within the first 2 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 right amount of information from a gastroenterologist. However, fewer in the Cohort sample reported that they received the right amount of information from the internet (19% vs. 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 last 10 years (15) and the much wider range of information available there (16-19).

Respondents in both samples thought 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 6), 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 (i.e., 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% vs. 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 to the newly diagnosed sample (68%).

DISCUSSION

The aim of this 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 2 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 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, gender 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 viewed as helpful. Further, demographic variables did not predict preferences, for instance, on information about new treatments although females rated the importance of information about new treatments slightly higher than males.

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. Persons with chronic health conditions in particular, 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 where 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 do an adequate job of addressing many of the topics identified as important by the respondents in this 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 concerning 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). This study contributes to the important first step of identifying relevant domains and information gaps for IBD patients.

This study has a number of 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.

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References

1. Lipkus IM. Numeric, verbal, and visual formats of conveying health risks: suggested best practices and future recommendations. *Med Decis Making* 2007; 27: 696–713.
2. 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 (8), E102.
3. Schwappach DL, Mülders V, Simic D, Wilm S, Thürmann PA. Is less more? Patients' preferences for drug information leaflets. *Pharmacoepidemiol Drug Saf.* 2011.
4. 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 Oct 11;327(7419):861.
5. Nair K, Dolovich L, Cassels A, McCormack J, Levine M, Gray J, Mann K, Burns S. What patients want to know about their medications. Focus group study of patient and clinician perspectives. *Can Fam Physician* 2002;48:104-10.
6. Raynor DK, Blenkinsopp A, Knapp P, Grime J, Nicolson DJ, Pollock K, Dorer G, Gilbody S, Dickinson D, Maule AJ, Spoor P. 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(5):iii, 1-160.
7. 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(4):305-12.
8. Mansfield JC, Tanner AR, Bramble MG. Information for patients about inflammatory bowel disease. *J R Coll Phys Lond.* 1997;31: 184–187.
9. Bernstein, K.I., Promislow, S., Carr, R., Rawsthorne, P., Walker, J.R., & Bernstein, C.N. The information needs and preferences of recently diagnosed patients with IBD. *Inflamm Bowel Dis* 2011; 17: 590-598.
10. Graff LA, Walker JR, Lix L, Clara I, Rawsthorne P, Rogala L, Miller N, Jakul L, McPhail C, Ediger J, Bernstein CN. The relationship of inflammatory bowel

- disease type and activity to psychological functioning and quality of life. *Clin Gastro Hepatol* 2006; 4: 1491-1501.
11. 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;149:916-924.
 12. 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(1): 137.
 13. Clara I, Lix LM, Walker JR, Graff LA, Miller N, Rogala L, Rawsthorne P, Bernstein CN. The Manitoba IBD Index: Evidence for a New and Simple Indicator of IBD Activity. *Am J Gastroenterol* 2009; 104:1754-63.
 14. Irvine EJ, Feagan B, Rochon J, Archambault A, Fedorak RN, Groll A, Kinnear D, Saibil F, Mc Donald JWD, 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: 287-296.
 15. Fox S, Purcell K. Chronic Disease and the Internet. Mar 24 2010. Available at: <http://www.pewinternet.org/Reports/2010/Chronic-Disease.aspx> Accessed June 20th, 2011.
 16. 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(1):e4.
 17. Miller EA, West DM, Wasserman M. Health information websites: characteristics of US users by race and ethnicity. *J Telemed Telecare* 2007;13(6):298-302.
 18. Rice RE. Influences, usage, and outcomes of Internet health information searching: multivariate results from the Pew surveys. *Int J Med Inform* 2006 Jan;75(1):8-28.
 19. 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 Apr 20;13(2):e33.
 20. Kessels, RPC. Patients' memory for medical information. *J Royal Soc Med* 2003; 96: 219-222.

21. Watson PW, McKinstry B. A systematic review of interventions to improve recall of medical advice in healthcare consultations. *J Royal Soc Med* 2009; 102:235-243.
22. 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(18):2400-2406.
23. Beckjord EB, Finney Rutten LJ, Squiers L, Arora NK, Volckmann L, Moser RP, 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(3), e20.
24. Bundorf MK, Wagner TH, Singer SJ, Baker LC. Who searches the internet for health information? *Health Serv Res* 2006;41(3 Pt 1):819-36.
25. Promislow S, Walker JR, Taheri M, Bernstein CN. How well does the Internet answer patients' questions about inflammatory bowel disease? *Can J Gastroenterol*. 2010 Nov; 24(11):671-7.
26. Siegel CA. Review article: explaining risks of inflammatory bowel disease therapy to patients. *Aliment Pharmacol Ther* 2011; 33: 23–32.
27. 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.

Table 1: Demographic and Disease Characteristics of Participants

	Total (n=271)
Male/Female	106/165
Mean Age (standard deviation)	46.5 (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 & 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/Non-University Certificate or Diploma/ Below Bachelor Degree	36.4%
Bachelor Degree	13.6%
Above Bachelor Degree	11.2%

Disease Characteristics

CD/UC/IBD-type unspecified	132/138/1
Mean Age at Diagnosis (standard deviation)	35.7 (14.4)
Mean Age at Onset of Symptoms (standard deviation)	31.0 (14.9)
Active disease (MIBDI)	52.1%
Quality of Life (IBDQ) Mean score (SD)	176.7 (29.3)
Poor quality of life (% with IBDQ < 170)	32.5%

Received Initial Diagnosis From

Family Doctor	19%
Gastroenterologist	64%
Nurse	1%
Surgeon	12%
Parent	0%
Someone else/Don't know	4%

TABLE 2A: Clinically-related 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	The right amount	Mean Rating (95% Confidence Interval)	Within First 2 Months		Currently	
				Rated As Very Important	Mean Rating (95% Confidence Interval)	Rated As Very Helpful	Mean Rating (95% Confidence Interval)
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 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)

Note. Participants rated how much information they received in each of these areas on a 7-point rating scale with the anchors 0-1 (none/a little), 2 (a moderate amount), 3 (just the right amount), and 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%) so 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 2B: Medical Treatment of 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	The right amount	Mean Rating (95% Confidence Interval)	Within First 2 Months		Currently	
				Rated As Very Important	Mean Rating (95% Confidence Interval)	Rated As Very Helpful	Mean Rating (95% Confidence Interval)
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)

Note. Participants rated how much information they received in each of these areas on a 7-point rating scale with the anchors 0-1 (none/a little), 2 (a moderate amount), 3 (just the right amount), and 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%) so 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 2C: Self-Management of 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	The right amount	Mean Rating (95% Confidence Interval)	Within First 2 Months		Currently	
				Rated As Very Important	Mean Rating (95% Confidence Interval)	Rated As Very Helpful	Mean Rating (95% Confidence Interval)
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)
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Note. Participants rated how much information they received in each of these areas on a 7-point rating scale with the anchors 0-1 (none/a little), 2 (a moderate amount), 3 (just the right amount), and 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%) so these scores were not included in the calculation of the mean rating. Each potential information topic was also rated on a 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: Ratings of Importance of Obtaining Information Concerning New Treatments for IBD.

Topic	Rated as Very Important	Mean Rating	95% Confidence Interval
A) The effectiveness of new medication	86%	7.1	(6.92-7.29)
B) The effectiveness of the new medication compared to 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)

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

Table 4: Multiple Regression With Demographic and Disease Characteristics as Predictors of Ratings of Importance of Information About a New Treatment

Variable	<i>b</i>	<i>beta</i>	<i>t</i>	<i>p</i>
Constant	6.17		11.04	.000
Sex	.330	.122	1.90	.059
Age	.143	.054	0.82	.408
Education	.003	.001	0.02	.985
CD/UC	.161	.061	0.93	.355
Disease activity	-.136	-.052	-0.79	.430

TABLE 5: Preferences for Source of Information Concerning a New Treatment

	Rated as very acceptable	Mean rating (95% confidence interval)	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 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)	--

Note. Each source of information was rated on a 9-point rating scale with the 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. Only information about the first ranked choice is shown here.

TABLE 6: Comparison of selected findings from the recently diagnosed sample* compared to the Cohort sample

	Recently diagnosed sample	Cohort sample
	N=74	N=271
Source providing the “right” amount of information within 2 months from 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%

*the data from the recently diagnosed sample (surveyed within 2 to 24 months of diagnosis) are reported in full in reference 9, Bernstein KI et al