

Supplementary Material

Table S1. Factor analysis of ratings of helpfulness of information at current time

Considering the information you already have about IBD, how helpful would it be for you to have more information in the following areas?	Domain					
	1	2	3	4	5	6
% of Variance	17.2	14.1	8.9	8.4	7.4	7.0
Domain 1: Managing symptoms, therapy & complications						
How to manage symptoms other than pain related to IBD	.71					
Possible side effects of medications	.70					
Medication treatments for IBD	.70					
How to manage pain related to IBD	.65					
Complications that may arise from IBD	.64					
How to adjust medications when symptoms cause more problems	.63					
Surgical treatments that may be required for IBD	.61					
Common symptoms of IBD	.54					
What is known (or not known) about the causes of IBD	.53					
When to contact your doctor	.45					
Domain 2: Nutrition						
What foods offer the best nutritional value	.88					
What nutritional deficiencies you may be at risk for	.87					
When to use nutritional supplements	.69					
Changes to diet that may be helpful when the disease is active	.64					
Changes to diet that may be helpful when the disease is inactive	.63					
Domain 3: Stress & coping						
How to deal psychologically with the diagnosis of IBD	.85					
Tools for dealing with stress which can affect the disease or can result from it	.75					
Sources of support in coping with IBD	.50					
Alternative medicine treatments for IBD	.40					
Domain 4: Family, society & religion						
How IBD may affect military service	.69					
Informing family members about IBD	.60					
Religious topics that may be related to IBD	.55					
Domain 5: Work & disability						
at their work place	.71					
How to manage time away from work or school related to IBD	.70					
How IBD or the medications may affect their fertility	.57					
Domain 6: Long term complications						
Long-term prognosis/outcome of IBD	.74					
The risk that patient's children have of developing IBD at some point in their life	.56					
	.53					

For each domain, items were listed according to their contribution to the variance within the domain

Table S2. Factor analysis of ratings of importance at disease onset

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:	Domain			
	1	2	3	4
% of Variance	19.3	15.5	15.4	11.5
Domain 1: Managing symptoms and therapy				
How to adjust medications when symptoms cause more problems	.74			
How to manage pain related to IBD	.72			
Medication treatments for IBD	.69			
When to contact your doctor	.66			
How to manage symptoms other than pain related to IBD	.65			
Possible side effects of medications	.56			
Changes to diet that may be helpful when the disease is active	.55			
Common symptoms of IBD	.53			
Insurance that may be available if they run out of sick days at their work place	.52			
How to manage time away from work or school related to IBD	.47			
Domain 2: Stress and coping				
How to deal psychologically with the diagnosis of IBD		.78		
Tools for dealing with stress which can affect the disease or can result from it		.73		
Sources of support in coping with IBD		.65		
Alternative medicine treatments for IBD		.60		
Informing family members about IB		.47		
How IBD may affect military service		.41		
Domain 3: Complications				
Risk of developing cancer			.72	
Complications that may arise from IBD			.71	
The risk that patient's children have of developing IBD at some point in their life			.69	
Surgical treatments that may be required for IBD			.64	
Long-term prognosis/outcome of IBD			.50	
What is known (or not known) about the causes of IBD			.49	
How IBD or the medications may affect their fertility			.48	
Religious topics that may be related to IBD			.33	
Domain 4: Nutrition				
What foods offer the best nutritional value				.78
What nutritional deficiencies you may be at risk for				.76
When to use nutritional supplements				.62
Changes to diet that may be helpful when the disease is inactive				.53

For each domain, items were listed according to their contribution to the variance within the domain

Table S3. Information domains derived from factor analysis of study items (**A.** Current needs **B.** Needs at disease onset)

A. Current information needs	
Domain 1	Managing symptoms, therapy & complications
Domain 2	Nutrition
Domain 3	Stress & coping
Domain 4	Family, society & religion
Domain 5	Work & disability
Domain 6	Long term complications
B. Information needs at disease onset	
Domain 1	Managing symptoms & therapy
Domain 2	Stress & coping
Domain 3	Complications
Domain 4	Nutrition

Table S4. Clinically significant disparities in rating of items. Analysis per compound patient profiles†

				Mean±CI‡ profile vs others	Delta*
		P1	patients with active disease (MIBDI A/B/C) and a history of hospitalization during the preceding 12 months		
Items	DC5	V126	How to manage time away from work or school related to IBD	7.2±0.3vs 5.5±0.3	1.7
	DC5	V125	How IBD or the medications may affect their fertility	6.7±0.5 vs 5.5±0.3	1.2
	DC1	V120	Surgical treatments that may be required for IBD	6.1±0.5 vs 5±0.3	1.1
	DC3	V139	How to deal psychologically with the diagnosis of IBD	6.9±0.4 vs 5.9±0.3	1
	DC1	V121	How to manage pain related to IBD	7±0.4 vs 6±0.2	1
		P3	patient in remission while treated with immunomodulators and/or biologics		
Items	DD3	V109	Risk of developing cancer	5.2±1.1 vs 6.6±0.1	-1.4
	DC1	V120	Surgical treatments that may be required for IBD	4± 1.2vs 5.3±0.2	-1.3
	DD3	V92	Surgical treatments that may be required for IBD	4.7±0.9 vs 6±0.2	-1.3
	DD3	V88	Complications that may arise from IBD	5.4±1 vs 6.6±0.2	-1.2
	DC1	V119	Possible side effects of medication treatments	5.4±1 vs 6.6±0.2	-1.2
	DD1	V91	Possible side effects of medication treatments	6.1±0.8 vs 7.1±0.1	-1
		P4	patients in remission while treated with mesalamine or receiving no treatment		
Items	DC3	V135	Sources of support in coping with IBD	4.5±0.6 vs 5.9±0.3	-1.4
	DC1	V121	How to manage pain related to IBD	5.1±0.6 vs 6.4±0.2	-1.3
	DC3	V139	How to deal psychologically with the diagnosis of IBD	5±0.7 vs 6.3±0.2	-1.3
	DC5	V126	How to manage time away from work or school related to IBD	4.8±0.7 vs 6±0.3	-1.2
	DC4	V142	Information on religious topics that may be related to IBD	2±0.7 vs 3.2±0.3	-1.2
	DC4	V134	Informing family members about IBD	2.7±0.7 vs 3.9±0.3	-1.2
		P5	patient aged 21-65 years with any disease activity (MIBDI A/B/C/D)		
Items	DC1	V121	How to manage pain related to IBD	6.7±0.2 vs 5.6±0.4	1.1
		P6	patients with any disease activity (MIBDI A/B/C/D), and a previous surgery for IBD		
Items	DC4	V134	Informing family members about IBD	4.6±0.7 vs 3.5±0.3	1.1
		P7	patients older than age 50 years, diagnosed during the preceding 12 months		
Items	DD3	V109	Risk of developing cancer	7.7±0.4 vs 6.5±0.2	1.2
	DC1	V116	Complications that may arise from IBD	6.9±0.8 vs 5.7±0.2	1.2
	DC5	V125	How IBD or the medications may affect their fertility	1.3±1.5 vs 5.8±0.2	-4.5
	DC5	V126	How to manage time away from work or school related to IBD	2.7±2.6 vs 5.9±0.2	-3.2
	DD2	V113	How IBD may affect military service	3.9±2.1 vs 6.2±0.2	-2.3
	DC6	V133	Risk that patients' children have of developing IBD at some point in their life	3.3±2.7 vs 5.6±0.2	-2.3
	DC4	V142	Information on religious topics that may be related to IBD	0.7±1.4 vs 3±0.3	-2.3
	DC4	V141	How IBD may affect military service	0.7±1.4 vs 2.9±0.3	-2.2
		P8	patient younger than age 21 years, diagnosed during the preceding 12 months		
Items	DC1	V122	How to manage symptoms other than pain related to IBD	3.9±1.7 vs 6.3±0.2	-2.4
	DD1	V95	How to adjust medications when symptoms cause more problems	5.3±1.5 vs 7.2±0.1	-1.9
	DC6	V133	Risk that patients' children have of developing IBD at some point in their life	3.9±1.9 vs 5.6±0.2	-1.7
	DD1	V99	Insurance that may be available if they run out of sick days at their work place	5.7±1.2 vs 7.2±0.2	-1.5

P, profile DD, Domains concerning information needs at Disease onset (DD 1-4) DC, Domains concerning Current information needs (DC 1-6)

V, Item number in the computerized questionnaire * All statistically significant at P<0.05 ‡95% confidence intervals

† Profile 2 not included due to lack of differences >1 (the cut off for clinical significance according to our definitions)

Table S5. Clinically significant disparities in rating of items. Analysis per simple patient profiles†

				Mean±CI† profile vs others	Delta*
		P11	patients diagnosed more than 10 years ago		
Items	DC5	V126	How to manage time away from work or school related to IBD	5.1±0.4 vs 6.3±0.3	-1.2
		P12	patients who had surgery during the preceding 12 months		
Items	DC1	V120	Surgical treatments that may be required for IBD	6.2±0.6 vs 5.2±0.2	1
		P13	patients with high disease activity (MIBDI A/B)		
Items	DC4	V134	Informing family members about IBD	4.3±0.4 vs 3.2±0.3	1.1
		P14	patients diagnosed at age > 50 years		
	DC4	V134	Informing family members about IBD	5.2±0.8 vs 3.5±0.3	1.7
	DC1	V124	When to contact your doctor	6.6±0.5 vs 5.3±0.3	1.3
	DC3	V135	Sources of support in coping with IBD	6.8±0.5 vs 5.5±0.3	1.3
	DC2	V132	When to use nutritional supplements	6.6±0.6 vs 5.4±0.3	1.2
	DC1	V115	Common symptoms of IBD	6.1±0.6 vs 4.9±0.3	1.2
	DC6	V137	Risk of developing cancer	7±0.4 vs 5.9±0.3	1.1
Items	DC6	V136	Long-term prognosis/outcome of IBD	7.2±0.4 vs 6.1±0.2	1.1
	DC2	V129	Changes to diet that may be helpful when the disease is inactive	7.2±0.4 vs 6.1±0.2	1.1
	DC1	V123	How to adjust medications when symptoms cause more problems	7.4±0.4 vs 6.3±0.2	1.1
	DC2	V131	What nutritional deficiencies you may be at risk for	7±0.4 vs 6±0.2	1
	DC5	V125	How IBD or the medications may affect their fertility	3.7±0.9 vs 6±0.2	-2.3
	DC5	V126	How to manage time away from work or school related to IBD	4.6±0.9 vs 6±0.2	-1.4
		P15	patients who were unemployed or received disability pension during the preceding 12 months		
	DC4	V141	How IBD may affect military service	4±1.2 vs 2.8±0.3	1.2
Items	DC4	V134	Informing family members about IBD	4.7±1.1 vs 3.6±0.3	1.1
	DC1	V124	When to contact your doctor	6.4±0.7 vs 5.3±0.3	1.1

P, profile DD, Domains concerning information needs at Diagnosis (DD 1-4) DC, Domains concerning Current information needs (DC 1-6)

V, Item number in the computerized questionnaire * All statistically significant at P<0.05 05 ‡ 95% confidence intervals

† Profiles 9,10 not included due to lack of differences >1 (the cut off for clinical significance according to our definitions)

Table S6

A list of the 28 “information items” included in the questionnaire (evaluating the given *amount* or perceived *importance* of the items)

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1. Common symptoms of IBD
 2. Complications that may arise from IBD
 3. What is known (or not known) about the causes of IBD
 4. Medication treatments for IBD
 5. Possible side effects of medications
 6. Surgical treatments that may be required for IBD
 7. How to manage pain related to IBD
 8. How to manage symptoms other than pain of IBD
 9. How to adjust medications when symptoms cause more problems
 10. When to contact your doctor
 11. How IBD or the medications may affect their fertility
 12. How to manage time away from work or school related to IBD
 13. Insurance coverage if they run out of sick days at their work place
 14. Changes to diet that may be helpful when the disease is active
 15. Changes to diet that may be helpful when the disease is inactive
 16. What foods offer the best nutritional value
 17. What nutritional deficiencies you may be at risk for
 18. When to use nutritional supplements
 19. Patient's children risk of developing IBD at some point in their life
 20. Informing family members about IBD
 21. Sources of support in coping with IBD
 22. Long-term prognosis/outcome of IBD
 23. Risk of developing cancer
 24. Alternative medicine treatments for IBD
 25. How to deal psychologically with the diagnosis of IBD
 26. Tools for dealing with stress affecting or resulting from the disease
 27. How IBD may affect military service
 28. Religious topics that may be related to IBD
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