Information Needs of Patients with Inflammatory Bowel Disease in the Digital Era: A 20-Year Longitudinal Study

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Article

Information Needs of Patients with Inflammatory Bowel Disease in the Digital Era: A 20-Year Longitudinal Study

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Abstract: Background :Chronic inflammatory bowel disease (IBD) significantly impacts patients' everyday lives. Despite receiving regular medical care in gastroenterological consultations, patients with IBD still experience a lack of information. To evaluate these deficits, we analysed the main points of interest raised in an online consultation forum offered as a supplementary resource for patients.Methods:We analysed 20 years of online consultation data at three time points: 2003 (launch of the forum), 2013, and 2024, and compared them against each other. A total of 681 patients participated in the consultations during these years. The clinical profiles of the participants included Crohn's disease (CD, n=209), ulcerative colitis (UC, n=139), unclassified colitis (IBDU, n=30), and individuals with no specified diagnosis (NSD, n=303).Results:Patients with UC were more interested in bowel-specific problems, extraintestinal manifestations involving skin and myalgia, diet/nutrition, weight, and treatment with biologics. Patients with CD were also interested in extraintestinal manifestations involving skin and myalgia, treatment with biologics, and diet/nutrition. Other areas of interest were imaging and laboratory analyses in the context of diagnostics, as well as pain therapy and drug dosage. Patients with IBDU were interested in disease flare-ups and treatment with biologics. NSD individuals sought information on topics such as skin manifestations and myalgia, general health deterioration, diet/nutrition, laboratory diagnostics, and pain therapy.Conclusion:For patients with IBD, online consultations serve as a valuable complement to standard medical care, offering additional support and helping to build confidence. A range of disease-related topics were consulted; however, the greatest interest centred on treatment and diagnostic options.

Keywords: inflammatory bowel diseases; information deficits; e-health; counselling; online consultations; biologics; therapy

1. Introduction

Inflammatory bowel disease (IBD) is a chronic disease for which the medical consultation format (traditional, digital) has improved in recent years. Despite the improvement in medical consultations, there may still be information gaps among patients with IBD. This study aimed to evaluate existing information deficits of patients with IBD in an online IBD consultation forum. The most important representatives were Crohn's disease (CD) and ulcerative colitis (UC).1 Approximately 10% of IBD cases cannot be accurately classified as CD or UC and are referred to as unclassified colitis (IBDU). Drug therapy aims to alleviate existing symptoms, reduce inflammation, and achieve remission. In addition to steroids, immunomodulators, biologics, integrin inhibitors, IL-12/23 or IL-23 blockers, 5-aminosalicylates, antibiotics, and other supportive medications are also used in IBD therapy. In severe situations that cannot be controlled with medication or if complications arise, surgery may be necessary. It has been demonstrated that patients with IBD are exposed to increased stress due to the

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complexity of the disease. Given the multiple problems of disease management and the high socioeconomic burden of IBD, we explored patients' questions in an online consultation forum.2,3,4,5,6

2. Material and Methods

In 2003, 2013, and 2024, we analysed the online consultation forum on the website "www.ced-hospital.de". 681 Patients participated in the consultation after registering in the forum, which they could access around the clock. The clinical profiles of the participants were categorised as CD (n=209), UC (139), IBDU (30), and no specified diagnosis (NSD, n=303). The content of the consultations was documented in detail and then categorised accordingly. This information was analysed using the "present=1" or "not present=0" coding. Statistical analyses were conducted using the SPSS for Windows program, version 29.0 (SPSS Inc., USA). The Chi-square and Fisher's exact tests were used as statistical test procedures. The assumption that fewer than 20 % of expected frequencies were below five was met for the chi-square test. All statistical tests were two-sided; a p-value < 0.05 was considered statistically significant.

3. Results

The analysis of the topics and focal points of the consultations for the four categories (CD, UC, IBDU, and NSD) presented significant changes over the years studied, i.e., 2003, 2013, and 2024. A comparison between 2003 and 2013, 2003 and 2024, and 2013 and 2024 revealed significant differences in the topics and focal points.

3.1. Ulcerative Colitis

1. 2003 vs 2013: The comparison of consultation topics between 2003 and 2013 revealed significant changes in patient interests. In most cases, interest declined over time, particularly in topics such as 5-aminosalicylates, relapse, disease complications, endoscopic diagnostics, and stress. However, interest increased in topics related to intestinal problems and skin changes as part of extraintestinal disease manifestations.
2. 2003 vs 2024: Significant differences were found when comparing 2003 and 2024. There was increased interest in diet/nutritional management, weight problems/malnutrition, extraintestinal disease manifestations focused on myalgia, and treatment with biologics. There was reduced interest in endoscopy and 5-aminosalicylate treatment.
3. 2013 vs 2024: When comparing 2013 and 2024, interest in bowel-specific problems, pain therapy, and 5-aminosalicylate treatment decreased. In contrast, there was an increase in diet/nutritional management and biologics.

3.2. Crohn's Disease

1. 2003 vs 2013: The comparison between 2003 and 2013 showed a significantly increased interest in diet/nutritional management and extraintestinal disease manifestations focused on skin and myalgia. In contrast, interest in hospitalisation, pain therapy, glucocorticoid treatment, and stress was significantly decreased.
2. 2003 vs 2024: When comparing 2003 and 2024, interest in bowel-specific problems, 5-aminosalicylate treatment, and general health deterioration dropped, while interest in diet/nutritional management, drug therapy with biologics, and diagnostic imaging procedures increased.
3. 2013 vs 2024: The comparison between 2013 and 2024 revealed a decreased interest in bowel-specific problems, 5-aminosalicylate treatment, and general health deterioration. There was a concomitant increase in diet/nutritional management, pain therapy, biologics, diagnostic imaging procedures, correct drug dosage, and stress.

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3.3. Unclassified Colitis

1. 2003 vs 2013: The comparison between 2003 and 2013 showed only one significant change, an increased interest in disease flare-ups.
2. 2003 vs 2024: A significantly increased interest in treatment with biologics was observed when comparing 2003 and 2024.
3. 2013 vs 2024: The comparison between 2013 and 2024 also showed a significant increase concerning treatment with biologics.

3.4. NSD

1. 2003 vs 2013: The comparison between 2003 and 2013 showed a significantly increased interest in extraintestinal disease manifestations focused on skin and general health deterioration. There was decreased interest in pain therapy, drug dosage, and stress.
2. 2003 vs 2024: Between 2003 and 2024, there was significantly reduced interest in four topics: bowel-specific problems, glucocorticoids, 5-aminosalicylates, and drug dosage. In contrast, there was increased interest in diet/nutritional management, extraintestinal disease manifestations focused on myalgia, and laboratory diagnostics.
3. 2013. vs 2024: Comparison of 2013 and 2024 again revealed significant differences. There was reduced interest in the topics of bowel-specific problems, 5-aminosalicylate treatment, and general health deterioration, along with increased interest regarding diet/nutritional management, pain therapy, and laboratory diagnostics.

The results of the comparisons of question categories between years for each disease entity are summarised in the following tables:

Ulcerative colitis (UC)

	Years and *p*-values			**Years and *p*-values**			**Years and *p*-values**		
Question categories	**2003**	**2013**	***p***	**2003**	**2024**	***p***	**2013**	**2024**	***p***
Intestinal-specific questions	7.4% (n=5)	21.6% (n=11)	0.031	7.4% (n=5)	0.0% (n=0)	0.584	21.6% (n=11)	0.0% (n=0)	0.027
Weight problems	1.5% (n=1)	2.0% (n=1)	1.000	1.5% (n=1)	15.0% (n=3)	0.035	2.0% (n=1)	15.0% (n=3)	0.065
Diet/Nutrition	2.9% (n=2)	5.9% (n=3)	0.650	2.9% (n=2)	35.0% (n=7)	<0.001	5.9% (n=3)	35.0% (n=7)	0.004
Disease Relapse	47.1% (n=32)	27.5% (n=14)	0.037	47.1% (n=32)	40.0% (n=8)	0.619	27.5% (n=14)	40.0% (n=8)	0.394
Hospitalisation	20.6% (n=14)	27.5% (n=14)	0.393	20.6% (n=14)	25.0% (n=5)	0.759	27.5% (n=14)	25.0% (n=5)	1.00
Complications	75.0% (n=51)	56.9% (n=29)	0.049	75.0% (n=51)	70.0% (n=14)	0.773	56.9% (n=29)	70.0% (n=14)	0.420
Arthropathies	23.5% (n=16)	15.7% (n=8)	0.359	23.5% (n=16)	20.0% (n=4)	1.000	15.7% (n=8)	20.0% (n=4)	0.729
Hepatopathies	1.5% (n=1)	5.9% (n=3)	0.312	1.5% (n=1)	0.0% (n=0)	1.000	5.9% (n=3)	0.0% (n=0)	0.554
Skin-related disease manifestations	0.0% (n=0)	9.8% (n=5)	0.013	0.0% (n=0)	0.0% (n=0)	1.000	9.8% (n=5)	0.0% (n=0)	0.312

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Eye-related disease manifestations	4.4% (n=3)	7.8% (n=4)	0.460	4.4% (n=3)	0.0% (n=0)	1.000	7.8% (n=4)	0.0% (n=0)	0.571
Myalgia	0.0% (n=0)	3.9% (n=2)	0.182	0.0% (n=0)	10.0% (n=2)	0.050	3.9% (n=2)	10.0% (n=2)	0.314
Pain Therapy	38.2% (n=26)	23.5% (n=12)	0.113	38.2% (n=26)	55.0% (n=11)	0.206	23.5% (n=12)	11.0% (n=11)	0.022
Biologics	1.5% (n=1)	5.9% (n=3)	0.312	1.5% (n=1)	50.0% (n=10)	<0.001	5.9% (n=3)	50.0% (n=10)	<0.001
Glucocorticoids	61.8% (n=42)	41.2% (n=21)	0.041	61.8% (n=42)	40.0% (n=8)	0.123	41.2% (n=21)	40.0% (n=8)	1.000
Antibiotics	22.1% (n=15)	23.5% (n=12)	1.000	22.1% (n=15)	10.0% (n=2)	0.339	23.5% (n=12)	10.0% (n=2)	0.321
5-Aminosalicylates	75.0% (n=51)	51.0% (n=26)	0.011	75.0% (n=51)	20.0% (n=4)	<0.001	51.0% (n=26)	20.0% (n=4)	0.031
Imaging	11.8% (n=8)	11.8% (n=6)	1.000	11.8% (n=8)	25.0% (n=5)	0.161	11.8% (n=6)	25.0% (n=5)	0.272
Endoscopy	47.1% (n=32)	21.6% (n=11)	0.007	47.1% (n=32)	20.0% (n=4)	0.039	21.6% (n=11)	20.0% (n=4)	1.000
Laboratory	26.5% (n=18)	39.2% (n=20)	0.166	26.5% (n=18)	35.0% (n=7)	0.574	39.2% (n=20)	35.0% (n=7)	0.792
Drug dosage	32.4% (n=22)	27.5% (n=14)	0.687	32.4% (n=22)	25.0% (n=5)	0.594	27.5% (n=14)	25.0% (n=5)	1.000
Stress	26.5% (n=18)	3.9% (n=2)	0.001	26.5% (n=18)	15.0% (n=3)	0.380	3.9% (n=2)	15.0% (n=3)	0.132
General Health Deterioration	39.7% (n=27)	47.1% (n=24)	0.458	39.7% (n=27)	35.0% (n=7)	0.797	47.1% (n=24)	35.0% (n=7)	0.431

Crohn's disease (CD)

	Years and *p*-values			**Years and *p*-values**			**Years and *p*-values**		
Question categories	**2003**	**2013**	***p***	**2003**	**2024**	***p***	**2013**	**2024**	***p***
Intestinal-specific questions	22.5% (n=20)	19.5% (n=16)	0.709	22.5% (n=20)	0.0% (n=0)	<0.001	19.5% (n=16)	0.0% (n=0)	0.003
Weight problems	1.1% (n=1)	7.3% (n=6)	0.056	1.1% (n=1)	0.0% (n=0)	1.000	7.3% (n=6)	0.0% (n=0)	0.175
Diet/Nutrition	0.0% (n=0)	11.0% (n=9)	0.001	0.0% (n=0)	36.8% (n=14)	<0.001	11.0% (n=9)	36.8% (n=14)	0.002
Disease relapse	23.6% (n=21)	17.1% (n=14)	0.345	23.6% (n=21)	26.3% (n=10)	0.822	17.1% (n=14)	26.3% (n=10)	0.326
Hospitalisation	37.1% (n=33)	18.3% (n=15)	0.007	37.1% (n=33)	31.6% (n=12)	0.686	18.3% (n=15)	31.6% (n=12)	0.157
Complications	65.2%	61.0%	0.635	65.2%	52.6%	0.233	61.0%	52.6%	0.430

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	(n=58)	(n=50)		(n=58)	(n=20)		(n=50)	(n=20)	
Arthropathies	22.5% (n=20)	20.7% (n=17)	0.853	22.5% (n=20)	18.4% (n=7)	0.813	20.7% (n=17)	18.4% (n=7)	1.000
Hepatopathies	2.2% (n=2)	7.3% (n=6)	0.155	2.2% (n=2)	0.0% (n=0)	1.000	7.3% (n=6)	0.0% (n=0)	0.175
Skin-related disease manifestations	3.4% (n=3)	14.6% (n=12)	0.013	3.4% (n=3)	7.9% (n=3)	0.363	14.6% (n=12)	7.9% (n=3)	0.383
Eye-related disease manifestations	5.6% (n=5)	7.3% (n=6)	0.760	5.6% (n=5)	5.3% (n=2)	1.000	7.3% (n=6)	5.3% (n=2)	1.000
Myalgia	1.1% (n=1)	9.8% (n=8)	0.015	1.1% (n=1)	5.3% (n=2)	0.213	9.8% (n=8)	5.3% (n=2)	0.501
Pain Therapy	32.6% (n=29)	12.2% (n=10)	0.002	32.6% (n=29)	50.0% (n=19)	0.074	12.2% (n=10)	50.0% (n=19)	<0.001
Biologics	18.0% (n=16)	18.3% (n=15)	1.000	18.0% (n=16)	52.6% (n=20)	<0.001	18.3% (n=15)	52.6% (n=20)	<0.001
Glucocorticoids	62.9% (n=56)	45.1% (n=37)	0.022	62.9% (n=56)	50.0% (n=19)	0.237	45.1% (n=37)	50.0% (n=19)	0.695
Antibiotics	19.1% (n=17)	24.4% (n=20)	0.459	19.1% (n=17)	26.3% (n=10)	0.356	24.4% (n=20)	26.3% (n=10)	0.824
5-Aminosalicylates	39.3% (n=35)	34.1% (n=28)	0.528	39.3% (n=35)	0.0% (n=0)	<0.001	34.1% (n=28)	0.0% (n=0)	<0.001
Imaging	19.1% (n=17)	14.6% (n=12)	0.542	19.1% (n=17)	39.5% (n=15)	0.025	14.6% (n=12)	39.5% (n=15)	0.004
Endoscopy	24.7% (n=22)	22.0% (n=18)	0.720	24.7% (n=22)	34.2% (n=13)	0.286	22.0% (n=18)	34.2% (n=13)	0.181
Laboratory	34.8% (n=31)	32.9% (n=27)	0.872	34.8% (n=31)	52.6% (n=20)	0.076	32.9% (n=27)	52.6% (n=20)	0.046
Drug dosage	28.1% (n=25)	15.9% (n=13)	0.066	28.1% (n=25)	36.8% (n=14)	0.401	15.9% (n=13)	36.8% (n=14)	0.018
Stress	14.6% (n=13)	3.7% (n=3)	0.017	14.6% (n=13)	26.3% (n=10)	0.135	3.7% (n=3)	26.3% (n=10)	<0.001
General Health Deterioration	39.3% (n=35)	48.8% (n=40)	0.222	39.3% (n=35)	13.2% (n=5)	0.003	48.8% (n=40)	13.2% (n=5)	<0.001

Unclassified Colitis (IBDU)

Question categories	**Years and *p*-values**			**Years and *p*-values**			**Years and *p*-values**		
	2003	**2013**	***p***	**2003**	**2024**	***p***	**2013**	**2024**	***p***
Intestinal-specific questions	42.9% (n=6)	40.0% (n=4)	1.000	42.9% (n=6)	0.0% (n=0)	0.115	40.0% (n=4)	0.0% (n=0)	0.234

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Weight problems	0.0% (n=0)	10% (n=1)	0.417	0.0% (n=0)	33.3% (n=2)	0.079	10.0% (n=1)	33.3% (n=2)	0.518
Diet/Nutrition	0.0% (n=0)	30.0% (n=3)	0.059	0.0% (n=0)	33.3% (n=2)	0.079	30.0% (n=)	33.3% (n=)	1.000
Disease relapse	7.1% (n=1)	50.0% (n=5)	0.050	7.1% (n=1)	33.3% (n=2)	0.202	50.0% (n=5)	33.3% (n=2)	0.633
Hospitalisation	35.7% (n=5)	60.0% (n=6)	0.408	35.7% (n=5)	16.7% (n=1)	0.613	60.0% (n=)	16.7% (n=)	0.145
Complications	78.6% (n=11)	80.0% (n=8)	1.000	78.6% (n=11)	50.0% (n=3)	0.303	80.0% (n=8)	50.0% (n=3)	0.299
Arthropathies	14.3% (n=2)	30.0% (n=3)	0.615	14.3% (n=2)	16.7% (n=1)	1.000	30.0% (n=3)	16.7% (n=1)	1.000
Hepatopathies	0.0% (n=0)	30.0% (n=3)	0.059	0.0% (n=0)	0.0% (n=0)	1.000	30.0% (n=3)	0.0% (n=0)	0.250
Skin-related disease manifestations	0.0% (n=0)	20.0% (n=2)	0.163	0.0% (n=0)	0.0% (n=0)	1.000	20.0% (n=2)	0.0% (n=0)	0.500
Eye-related disease manifestations	0.0% (n=0)	20.0% (n=2)	0.163	0.0% (n=0)	16.7% (n=1)	0.300	20.0% (n=2)	16.7% (n=1)	1.000
Myalgia	0.0% (n=0)	30.0% (n=3)	0.059	0.0% (n=0)	16.7% (n=1)	0.300	30.0% (n=3)	16.7% (n=1)	1.000
Pain Therapy	35.7% (n=5)	50.0% (n=5)	0.678	35.7% (n=5)	66.7% (n=4)	0.336	50.0% (n=5)	66.7% (n=4)	0.633
Biologics	14.3% (n=2)	10.0% (n=1)	1.000	14.3% (n=2)	66.7% (n=4)	0.037	10.0% (n=1)	66.7% (n=4)	0.036
Glucocorticoids	42.9% (n=6)	50.0% (n=5)	1.000	42.9% (n=6)	50.0% (n=3)	1.000	50.0% (n=5)	50.0% (n=3)	1.000
Antibiotics	21.4% (n=3)	40.0% (n=4)	0.393	21.4% (n=3)	50.0% (n=3)	0.303	40.0% (n=4)	50.0% (n=3)	1.000
5-Aminosalicylates	35.7% (n=5)	30.0% (n=3)	1.000	35.7% (n=5)	16.7% (n=1)	0.613	30.0% (n=3)	16.7% (n=1)	1.000
Imaging	14.3% (n=14)	40.0% (n=10)	0.192	14.3% (n=2)	50.0% (n=3)	0.131	40.0% (n=4)	50.0% (n=3)	1.000
Endoscopy	50.0% (n=7)	70.0% (n=7)	0.421	50.0% (n=7)	50.0% (n=3)	1.000	70.0% (n=)	50.0% (n=)	0.607
Laboratory	35.7% (n=5)	70.0% (n=7)	0.214	35.7% (n=5)	66.7% (n=4)	0.336	70.0% (n=7)	66.7% (n=4)	1.000
Drug dosage	35.7% (n=5)	70.0% (n=7)	0.214	35.7% (n=5)	50.0% (n=3)	0.642	70.0% (n=7)	50.0% (n=3)	0.607
Stress	21.4% (n=3)	20.0% (n=2)	1.000	21.4% (n=3)	16.7% (n=1)	1.000	20.0% (n=2)	16.7% (n=1)	1.000
General Health Deterioration	50.0%	60.0%	0.697	50.0%	33.3%	0.642	60.0%	33.3%	0.608

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	(n=7)	(n=6)		(n=7)	(n=2)		(n=6)	(n=2)	
No specified disease (NSD)									
	Years and *p*-values			**Years and *p*-values**			**Years and *p*-values**		
Question categories	**2003**	**2013**	***p***	**2003**	**2024**	***p***	**2013**	**2024**	***p***
Intestinal-specific questions	14.3% (n=10)	14.1% (n=14)	1.000	14.3% (n=10)	0.0% (n=0)	<0.001	14.1% (n=14)	0.0% (n=0)	<0.001
Weight problems	1.4% (n=1)	2.0% (n=2)	1.000	1.4% (n=1)	2.2% (n=3)	1.000	2.0% (n=2)	2.2% (n=3)	1.000
Diet/Nutrition	1.4% (n=1)	6.1% (n=6)	0.241	1.4% (n=1)	17.2% (n=23)	<0.001	6.1% (n=6)	17.2% (n=23)	0.015
Disease relapse	7.1% (n=5)	7.1% (n=7)	1.000	7.1% (n=5)	6.0% (n=8)	0.768	7.1% (n=7)	6.0% (n=8)	0.791
Hospitalisation	17.1% (n=12)	20.2% (n=20)	0.693	17.1% (n=12)	11.9% (n=16)	0.391	20.2% (n=20)	11.9% (n=16)	0.100
Complications	47.1% (n=33)	60.6% (n=60)	0.087	47.1% (n=33)	47.8% (n=64)	1.000	60.6% (n=60)	47.8% (n=64)	0.063
Arthropathies	7.1% (n=5)	9.1% (n=9)	0.780	7.1% (n=5)	9.0% (n=12)	0.793	9.1% (n=9)	9.0% (n=12)	1.000
Hepatopathies	1.4% (n=1)	2.0% (n=2)	1.000	1.4% (n=1)	0.0% (n=0)	0.343	2.0% (n=2)	0.0% (n=0)	0.179
Skin-related disease manifestations	0.0% (n=0)	8.1% (n=8)	0.021	0.0% (n=0)	3.7% (n=5)	0.167	8.1% (n=8)	3.7% (n=5)	0.163
Eye-related disease manifestations	0.0% (n=0)	0.7% (n=1)	1.000	0.0% (n=0)	0.7% (n=1)	1.000	0.0% (n=0)	0.7% (n=1)	1.000
Myalgia	0.0% (n=0)	3.0% (n=3)	0.268	0.0% (n=0)	8.2% (n=11)	0.017	3.0% (n=3)	8.2% (n=11)	0.161
Pain Therapy	25.7% (n=18)	8.1% (n=8)	0.002	25.7% (n=18)	32.1% (n=43)	0.421	8.1% (n=8)	32.1% (n=43)	<0.001
Biologics	12.9% (n=9)	12.1% (n=12)	1.000	12.9% (n=9)	20.1% (n=27)	0.247	12.1% (n=12)	20.1% (n=27)	0.114
Glucocorticoids	38.6% (n=27)	29.3% (n=29)	0.246	38.6% (n=27)	18.7% (n=25)	0.004	29.3% (n=29)	18.7% (n=25)	0.061
Antibiotics	4.3% (n=3)	10.1% (n=10)	0.242	4.3% (n=3)	11.9% (n=16)	0.082	10.1% (n=10)	11.9% (n=16)	0.834
5-Aminosalicylates	20.0% (n=14)	25.3% (n=25)	0.463	20.0% (n=14)	6.0% (n=8)	0.004	25.3% (n=25)	6,0% (n=8)	<0.001
Imaging	8.6% (n=6)	10.1% (n=10)	0.796	8.6% (n=6)	14.9% (n=20)	0.269	10.1% (n=10)	14.9% (n=20)	0.326

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Endoscopy	18.6% (n=13)	23.2% (n=23)	0.568	18.6% (n=13)	20.1% (n=27)	0.854	23.2% (n=23)	20.1% (n=27)	0.629
Laboratory	17.1% (n=12)	17.2% (n=17)	1.000	17.1% (n=12)	51.5% (n=69)	<0.001	17.2% (n=17)	51.5% (n=69)	<0.001
Drug dosage	31.4% (n=22)	13.1% (n=13)	0.006	31.4% (n=22)	17.2% (n=23)	0.032	13.1% (n=13)	17.2% (n=23)	0.465
Stress	14.3% (n=10)	3.0% (n=3)	0.009	14.3% (n=10)	7.5% (n=10)	0.140	3.0% (n=3)	7.5% (n=10)	0.247
General Health Deterioration	14.3% (n=10)	32.3% (n=32)	0.011	14.3% (n=10)	13.4% (n=18)	0.834	32.3% (n=32)	13.4% (n=18)	<0.001

4. Discussion

In our study, we observed a wide range of focal points of interest among the forum participants analysed. At the beginning of the study (2003), patients with UC or CD were interested in bowel-specific problems, but this was no longer the case in 2024. NSD individuals were also initially interested in bowel-specific problems; however, this also declined over the years.

This decline could be due to the further development of therapeutic approaches for IBD treatment. The first biologics, in particular, anti-TNF-alpha, were authorised in 2003. Treatment with biologics allows for a more rapid modulation of inflammatory processes, thereby enabling longer symptom-free intervals for patients.7,8 The use of modern biological therapies, immunomodulators, and targeted IBD treatments could improve disease control such that patients were likely less focused on these topics due to reduced intestinal symptoms.

Among the patients with UC, it was notable that weight, particularly diet/nutrition, received greater attention in 2024, having been little discussed in previous years. Diet played a significant role for patients with CD as of 2013 and continued to do so until the end of the study. NSD individuals also showed an increased interest in nutrition, which was an important topic in 2024. In patients with UC, a good nutritional status directly influences disease activity, symptom severity, inflammatory parameters, and the risk of undergoing surgery.9

The literature had previously discussed whether there could be diet-related risk factors for IBD. Furthermore, it was also questioned whether dietary and nutritional interventions were helpful in IBD.10 Meanwhile, nutritional management has been afforded a high priority in treating patients with IBD, and nutritional therapy has found its way into the published guidelines.11,12

Both under- and overnutrition were key topics. In particular, patients with active CD were found to have impaired nutrient intake.12 In countries with rising obesity rates, a greater number of adult patients with IBD were also found to be obese.

This phenomenon could also affect disease progression. For this reason, in addition to nutritional management, preventive nutrition is now recommended, which is particularly popular with patients with CD.12 Our study reflects the growing relevance of nutrition in the context of IBD in recent years, not only in medical care but also in the daily lifestyle of patients with IBD.

At the beginning of our study, the topics of disease relapse and complications were favoured by many patients with UC; however, this declined in 2013 and did not generate any additional interest thereafter. Those with IBDU were also interested in disease flare-ups, which increased as of 2013 and remained steady.

During an IBD episode, patients with chronic IBD can experience increased malabsorption or malnutrition, which, in turn, triggers diarrhoea and abdominal pain. These symptoms occur both during existing disease activity and remission.14 Advances in drug therapies and treatment regimens have helped to manage these symptoms better, which may explain why this issue no longer appears to represent a major burden for patients with UC over time.

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The situation was different for patients with IBDU, who had the same symptoms as those with CD or UC. As a definitive diagnosis had not yet been made, the uncertainty regarding the origin of the symptoms may have led these patients to observe themselves more closely and regularly discuss or question their symptoms.

In the case of patients with CD, the focus was on the topic of hospitalisation, which became significantly less important over the course of the study. Some studies have shown that patients with CD experience more severe complications and thus are hospitalised more frequently than those with UC. This is partly because CD is more often associated with severe disease progression or additional complications, such as fistulas or stenoses, which require more intensive and frequent hospital treatment. This likely explains the greater interest in the topic among patients with CD.15,1

Another area of interest was extraintestinal manifestations of UC involving the skin, which increased in 2013 and then fell again. However, it was striking that in 2024, patients with UC were interested in extraintestinal disease manifestations involving myalgia, which was not the case in 2003.

Concerning extraintestinal disease manifestations involving skin and myalgia in CD, there was a particularly notable increased interest in 2013, which remained constant in 2024. For NSD individuals, interest in chronic IBD extraintestinal manifestations involving skin increased significantly in 2013, and those involving myalgia also increased in 2024. This demonstrates that patients were increasingly interested in new treatment options over time.

An extraintestinal manifestation of the disease can occur in both CD and UC. The muscles, skeleton, and skin are most frequently involved; however, the eyes, liver, gallbladder, pancreas, kidneys, and lungs can also be affected.17,18

The treatment of extraintestinal symptoms depends on their type. Conditions such as peripheral arthritis, episcleritis, and erythema nodosum are often associated with a flare-up and can be improved as part of IBD treatment.18

Extraintestinal symptoms such as uveitis, ankylosing spondylitis, and primary sclerosing cholangitis usually occur independently of disease activity. Thus, treatment of intestinal inflammation does not necessarily affect extraintestinal symptoms.18

In addition to conventional pain therapy and the classic medications used in IBD treatment, it was demonstrated that the use of vedolizumab led to a significant improvement in symptoms and positively affected quality of life.17,18

Vedolizumab was approved as a biologic for treating moderate to severe CD in 2014 and for UC in 2016. As it was used to treat extraintestinal symptoms, the interest in this new treatment option was understandable.

In the area of drug therapy, pain therapy played an important role for patients with UC, although this was less favoured at the end of the study period. Alongside pain therapy, 5-aminosalicylate treatment initially played a significant role; however, interest in this topic also declined over the years. In contrast, interest in treatment with biologics steadily increased among patients with UC over the years. Patients with CD were also interested in pain therapy at the beginning of the study, which decreased significantly and then increased again over time, with interest in this topic continuing until the end of the study. There was a slight drop in interest in glucocorticoid therapy, which remained constant. Patients with CD were also interested in biologics. The situation was different for 5-aminosalicylate treatment. Here, the initially favoured topic dropped significantly in 2024. Regarding drug therapy, patients with IBDU were interested in biologics, which were particularly favoured at the end of the study. Pain therapy was also favoured by NSD individuals. After an initial significant loss of interest in this topic, there was renewed interest throughout the study. Interest in glucocorticoid and 5-aminosalicylate treatments decreased during the study period among NSD individuals. Abdominal pain is a common issue among IBD patients.13 Up to 60% of patients with CD or UC have chronic pain, which can impair their quality of life and lead to considerable psychological stress.19 For some patients with CD or UC, abdominal pain could become a problem that lasts many years.9

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In addition to nonsteroidal anti-inflammatory drug (NSAID) therapy, opioids and cannabis have been used for pain control. Long-term use of opioids could lead to drug dependence, constipation, confusion, nausea, vomiting, and even sedation in patients with IBD.21

The literature indicates that, besides intestinal pain, the most common pain localisations were the back, joints, and head. Furthermore, pain tends to persist longer in patients with CD than in those with UC.22 The increased pain symptoms in patients with CD could account for the continued interest in pain therapy.

One apparent reason for the interest of patients with UC in biologics could be the possible occurrence of pouchitis, a common complication in UC.23 Patients with UC often develop chronic antibiotic-dependent or antibiotic-refractory pouchitis while undergoing drug therapy. An alternative drug therapy became available with the approval of vedolizumab as a biologic in 2022, which was more effective and could, therefore, have increased the interest in this topic.24

In IBD treatment, glucocorticoids are used to achieve clinical remission. Therapy is usually initiated at a higher dose, which can be gradually reduced after combination with other medications. Glucocorticoids can improve IBD symptoms and can be used in a variety of ways (topically or systemically), depending on the intestinal localisation requiring treatment. However, the serious side effects of glucocorticoid therapy, such as hyperglycaemia, high blood pressure, mood disorders, stomach ulcers, increased susceptibility to infections, and, in the long term, osteoporosis, are problematic. This could be a possible reason why patients were increasingly interested in glucocorticoids. As described above, interest in 5-aminosalicylates decreased in patients with CD. 5-aminosalicylate preparations have no proven effect in CD treatment; they are not recommended for induction therapy or for maintaining remission. However, they are still frequently used in treatment.25,26 Due to this effect, it did not seem thematically relevant for patients with CD.

At the beginning of our study, endoscopic diagnostics was an important area of interest for patients with UC; however, the interest declined over time. Regarding diagnostics, the areas of interest among patients with CD were imaging and laboratory diagnostics; interest in both areas increased towards the end of the study. Laboratory diagnostics were favoured by NSD individuals, which particularly increased in 2024.

Over the past few years, the determination of faecal calprotectin has been increasingly used as a diagnostic test to assess disease activity. With the introduction of the test and its associated reliability, a non-invasive tool could now be implemented in diagnostics, which led to a reduction in invasive colonoscopies examinations.27,28 This reduction in colonoscopies also led to a decrease in physical effort, which may have diminished the interest in this topic.29

In recent years, radiological and laboratory examination methods have developed alongside endoscopic methods and are regularly used to diagnose chronic IBD. In CD, studies have demonstrated a correlation between C-reactive protein measured by laboratory tests and the number of relapses, their severity, and the cumulative number of days of corticosteroid use. Thus, this topic has attracted great interest among patients with CD.30

Another reason for the increased interest in imaging procedures is their expanding use. In addition to conventional computed tomography (CT) or magnetic resonance imaging (MRI), capsule endoscopy has also been used in imaging procedures. In 2010, capsule endoscopy was also authorised for coverage by statutory healthcare insurance for cases of unexplained minor intestine bleeding, allowing for more frequent use, particularly for CD. Capsule endoscopy has proven very suitable for detecting small intestine lesions in known CD. MRI has also established itself as a successful method for risk-free examination of the small intestine, which can be used safely during pregnancy and in cases of kidney disease. Specific intestine-specific issues can be clarified via imaging instead of endoscopic procedures, which is a benefit and a relief for patients with IBD.30,31

The topic of drug dosage garnered increasing attention among patients with CD. While initially it was also of interest to NSD individuals, this diminished over time. Studies on patient preferences in chronic IBD have confirmed that, for patients with CD, understanding the risks and gaining

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sufficient knowledge about drug therapies could positively influence drug acceptance and compliance.32

Regarding stress, interest among patients with CD initially decreased but later increased. Stress was also a concern for NSD individuals, although interest in this topic decreased significantly in 2013.

Due to the progression of the disease (unpredictability of the next flare-up, abdominal pain, diarrhoea, family, professional, and financial situations, fear of pain and painful examinations, etc.), patients with IBD are exposed to a variety of stressful situations.33

Many patients with IBD experienced a significant reduction in quality of life due to the numerous stressful situations they faced. This stress could negatively impact disease progression, leading many patients to become more attuned to their physical sensations, which in turn could contribute to a range of psychosomatic problems.34,35 Given this, it seems reasonable that interest in the topic of stress increased over time.

In patients with CD, attention was also focused on the deterioration of their general health, although this diminished over the course of the study. Finally, NSD individuals were also interested in the topic of general health deterioration, which initially increased and then lost significance over time. The greatest challenges faced by patients with IBD are the unpredictable progression of the disease, frequent medical consultations, and potential hospitalisation. The possible side effects of the medication were an additional burden. This was associated with emotional turmoil, which hindered patients' ability to pursue a normal lifestyle and maintain a good quality of life.36 The high level of interest in general health deterioration was, therefore, explicable.

5. Strengths and Weaknesses

The interpretation of our results is subject to some limitations. The IBDU sample was very small. Moreover, it cannot be ruled out that the NSD group included not only patients but also relatives. Another study limitation was that forum participants were not directly assessed via a questionnaire. Therefore, the necessary information (e.g., gender, age, patient or relative) could have been collected better. A questionnaire could have also been used for a better differentiation of pain. Studies on the time required to organise and manage such an online forum must be conducted to enable interested practitioners to develop a time management system. As the online platform was non-commercial, its reach was limited. Nonetheless, our study suggests that it could be a valuable complement to online counselling for patients with IBD. Due to the small sample size, the results can only be generalised to patients with IBD to a limited extent. Nevertheless, they offer initial insights into the needs that may be relevant in the counselling of individual patients and their families. A follow-up evaluation after a further 10 years was, therefore, appropriate.

6. Conclusions

In summary, moderated online counselling offers many advantages over traditional face-to-face counselling. Based on these results, optimised interventions and strategies for healthcare can be developed. The findings presented herein may serve as a basis for developing topic guidelines to support higher-quality care for patients with IBD and their families. Conducting similar studies in this or other health forums could provide further insights to improve healthcare for patients with IBD.

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References

1. Janowitz, H. D., Burril, B. Crohn (1884-1983) Life and work.
2. Silverberg, M. S., Satsangi, J., Ahmad, T., et al. Toward an integrated clinical, molecular and serological classification of inflammatory bowel disease; Report of a Working Party of the 2005 Montreal World Congress of Gastroenterology. Can J Gastroenterol 2005; 19:5-35.
3. Sweeney, L., et al. "Systematic review: psychosocial factors associated with pain in inflammatory bowel disease." Alimentary pharmacology & therapeutics 47.6 (2018):715-729.
4. Kucharzik, T. et al. Updated S3 guideline ulcerative colitis. German Society for Digestive and Metabolic Diseases (DGVS) 2018.
5. Larsen, S., Bentzen, K., Nielsen, O. H. Extraintestinal manifestations of inflammatory bowel disease: epidemiology, diagnosis and management. Annals of Medicine 2010; 42:97-114.
6. Raine, Tim, et al. "ECCO guidelines on therapeutics in ulcerative colitis: medical treatment." Journal of Crohn's and Colitis 16.1 (2022): 2-17.
7. Chouraki, V., Savoye, G., Dauchet, L., Vernier-Massouille, G., Dupas, J.-L., Merle, V., Lauberenne, J.-E., Salomez, J.-L., Lerebours, E., Turck, D., Cortot, A., Gower-Rousseau, C., Colombel, J. F. The Changing pattern of Crohn's disease incidence in northern France: a continuing increase in the 10-to 19-year-old age bracket (1988-2007), Alimentary Pharmacology Ther 2011; 33:1133-1142.
8. Feagan, Brian G., Julián Panés, Marc Ferrante, Arthur Kaser, Geert R. D'Haens, William J. Sandborn, Edouard Louis et al. "Risankizumab in patients with moderate to severe Crohn's disease: an open-label extension study." *The Lancet Gastroenterology & Hepatology* 3, no. 10 (2018): 671-680.
9. Marsh, A., Rindfleish, S., Bennett, K., Croft, A., & Chachay, V. (2022). Outcomes of dietary management approaches in active ulcerative colitis: a systematic review. Clinical Nutrition, 41(2), 298-306.
10. Yamamoto, T., Nakahigashi, M., & Saniabadi, A. R. (2009). Nutrition and inflammatory bowel disease - epidemiology and treatment. Pharmacology and Therapeutics of Nutrition, 30(2), 99-112.
11. Halmos, E. P., & Gibson, P. R. (2015). Dietary management of IBD-insights and advice. *Nature Reviews Gastroenterology & Hepatology*, *12*(3), 133-146.
12. Fitzpatrick, J. A., Melton, S. L., Yao, C. K., Gibson, P. R., & Halmos, E. P. (2022). Nutritional management in adults with IBD - The emerging role of nutritional therapy. Nature Reviews Gastroenterology & Hepatology, 19(10), 652-669.
13. Aghdassi, E., Wendland, B. E., Stapleton, M., Raman, M., & Allard, J. P. (2007). Adequacy of nutritional intake in a Canadian population of patients with Crohn's disease. Journal of the American Dietetic Association, 107(9), 1575-1580.
14. Sweeney, L., Moss-Morris, R., Czuber-Dochan, W., Meade, L., Chumbley, G., & Norton, C. (2018). Systematic review: psychosocial factors associated with pain in inflammatory bowel disease. *Alimentary pharmacology & therapeutics*, *47*(6), 715-729.
15. sai, L., Nguyen, N. H., Ma, C., Prokop, L. J., Sandborn, W. J., & Singh, S. (2022). Systematic review and meta-analysis: risk of hospitalisation in patients with ulcerative colitis and Crohn's disease in population-based cohort studies. *Digestive diseases and sciences*, *67*(6), 2451-2461.
16. Nguyen, G. C., Bernstein, C. N., & Benchimol, E. I. (2017). Risk of surgery and mortality in elderly-onset inflammatory bowel disease: a population-based cohort study. *Inflammatory bowel diseases*, *23*(2), 218-223.
17. Levine, J. S., & Burakoff, R. (2011). Extraintestinal manifestations of inflammatory bowel disease. Gastroenterology & hepatology, 7(4), 235.
18. Rogler, G., Singh, A., Kavanaugh, A., & Rubin, D. T. (2021). Extraintestinal manifestations of inflammatory bowel disease: current concepts, treatment, and implications for disease management. Gastroenterology, 161(4), 1118-1132.
19. Coates, M. D., Johri, A., Gorrepati, V. S., Maheshwari, P., Dalessio, S., Walter, V., ... & Clarke, K. (2021). Abdominal pain in quiescent inflammatory bowel disease. *International journal of colorectal disease*, *36*, 93-102.

 doi:10.20944/preprints202504.2574.v1

20. Marsh, A., Rindfleish, S., Bennett, K., Croft, A., & Chachay, V. (2022). Outcomes of dietary management approaches in active ulcerative colitis: a systematic review. Clinical Nutrition, 41(2), 298-306.
21. McNicol, E. (2008). Opioid side effects and their treatment in patients with chronic cancer and noncancer pain. *Journal of Pain & Palliative Care Pharmacotherapy*, *22*(4), 270-281.
22. Zeitz, J., Ak, M., Müller-Mottet, S., Scharl, S., Biedermann, L., Fournier, N., ... & Swiss IBD Cohort Study Group. (2016). Pain in IBD patients: very frequent and frequently insufficiently taken into account. *PloS one*, *11*(6), e0156666.
23. Chandan, S., Mohan, B. P., Kumar, A., Khan, S. R., Chandan, O. C., Kassab, L. L., ... & Kochhar, G. S. (2021). Safety and efficacy of biological therapy in chronic antibiotic refractory pouchitis: a systematic review with meta-analysis. *Journal of Clinical Gastroenterology*, *55*(6), 481-491.
24. Manthey, C. F., Reher, D., & Huber, S. (2021). What is certain in the treatment of chronic inflammatory bowel diseases. The internist, 62(12), 1269.
25. Sturm, A., Atreya, R., Bettenworth, D., Bokemeyer, B., Dignaß, A., Ehehalt, R., ... & Stallmach, A. (2022). Updated S3 guideline "Diagnostics and therapy of Crohn's disease "of the German Society for Gastroenterology, Digestive and Metabolic Diseases (DGVS)-August 2021-AWMF registry number: 021-004. *Journal of Gastroenterology*, *60*(03), 332-418.
26. Torres, J., Bonovas, S., Doherty, G., Kucharzik, T., Gisbert, J. P., Raine, T., ... & Fiorino, G. (2020). ECCO guidelines on therapeutics in Crohn's disease: medical treatment. *Journal of Crohn's and Colitis*, *14*(1), 4-22.
27. Rokkas, T., Portincasa, P., & Koutroubakis, I. E. (2018). Fecal calprotectin in assessing inflammatory bowel disease endoscopic activity: a diagnostic accuracy meta-analysis. *Journal of Gastrointestinal and Liver Diseases*, *27*(3), 299-306.
28. Lin, J. F., Chen, J. M., Zuo, J. H., Yu, A., Xiao, Z. J., Deng, F. H., ... & Jiang, B. (2014). Meta-analysis: fecal calprotectin for assessment of inflammatory bowel disease activity. *Inflammatory bowel diseases*, *20*(8), 1407-1415.
29. Wang, W., Cao, W., Zhang, S., Chen, D., & Liu, L. (2025). The Role of Calprotectin in the Diagnosis and Treatment of Inflammatory Bowel Disease. *International Journal of Molecular Sciences*, *26*(5), 1996.
30. Moscandrew, M. E., & Loftus Jr, E. V. (2009). Diagnostic advances in inflammatory bowel disease (imaging and laboratory). *Current gastroenterology reports*, *11*(6), 488-495.
31. Gourtsoyiannis, N. C., Grammatikakis, J., Papamastorakis, G., Koutroumbakis, J., Prassopoulos, P., Rousomoustakaki, M., & Papanikolaou, N. (2006). Imaging of small intestinal Crohn's disease: comparison between MR enteroclysis and conventional enteroclysis. *European radiology*, *16*, 1915-1925.
32. Lichtenstein, G. R., Waters, H. C., Kelly, J., McDonald, S. S., Zanutto, E. L., Hendricks, D., & Rahman, M. I. (2010). Assessing drug treatment preferences of patients with Crohn's disease: a conjoint analysis. *The Patient: Patient-Centered Outcomes Research*, *3*, 113-123.
33. Hood, M. M., & Jedel, S. (2017). Mindfulness-based interventions in inflammatory bowel disease. *Gastroenterology Clinics*, *46*(4), 859-874.
34. Rubin, D. T., Siegel, C. A., Kane, S. V., Binion, D. G., Panaccione, R., Dubinsky, M. C., ... & Hopper, J. (2009). Impact of ulcerative colitis from patients' and physicians' perspectives: Results from the UC: NORMAL survey. *Inflammatory bowel diseases*, *15*(4), 581-588.
35. Melinder, C., Hiyoshi, A., Fall, K., Halfvarson, J., & Montgomery, S. (2017). Stress resilience and the risk of inflammatory bowel disease: a cohort study of men living in Sweden. *BMJ open*, *7*(1), e014315.
36. Byron, C., Cornally, N., Burton, A., & Savage, E. (2020). Challenges of living with and managing inflammatory bowel disease: A meta-synthesis of patients' experiences. *Journal of clinical nursing*, *29*(3-4), 305-319.