

Results from the NACC Survey of IBD Symptoms including Pain (survey May 2004) (report revised 2008)

The aim of the survey was to explore the range of symptoms that patients with Ulcerative Colitis or Crohn's Disease experience and, in particular, to understand more about how pain affects their lives.

The survey was sent to 5,000 members and these results reflect the analysis of the first 2,527 responses received.

Demographics

Responses came from 1673 women and 844 men, with almost equal numbers of women having Ulcerative Colitis (UC) or Crohn's Disease (CD), but more men having Ulcerative Colitis (57%) than Crohn's. The age profile was very close to that of the NACC membership. Among the younger age group, there were slightly more women than men, and slightly more patients with Crohn's Disease. The older groups were slightly more likely to have Ulcerative Colitis.

	Totals	aged under 28	aged 29 – 45	aged 46 – 65	Aged over 65
	%	%	%	%	%
All	100	9	33	38	20
Women	66	11	36	36	18
Men	33	7	29	42	24
UC	49	6	31	40	21
CD	49	12	35	35	16

Other Related or Serious Medical Conditions

We wished to identify other possible causes of pain and therefore asked people to say if they had another related or serious medical condition. The larger groups were:

6% reported a diagnosis of Arthritis, 2 % reported joint problems and another 2% osteoarthritis. 1% had Ankylosing Spondylitis; 1% reported back problems. 5% had Osteoporosis.

4% Asthma, 3% Diabetes and 3% Blood Pressure problems. 1% said they had Irritable Bowel Syndrome.

Surgical Treatment for IBD

12% of those who have Ulcerative Colitis had had surgery, compared with 58 % of those who have Crohn’s Disease. (34% of the whole sample.) The operations most commonly mentioned were these – some people had had more than one type of operation.

	UC %	CD %
Strictureplasty	6	9
Resection	19	70
Colostomy	17	8
Permanent Ileostomy	21	11
Temporary Ileostomy	11	9
Ileo-anal Pouch	25	0
Unspecified operations to remove bowel	9	11

Number of Flare-ups in the last Two years

67% of those who responded to the survey had had a flare-up of their Ulcerative Colitis or Crohn’s Disease in the last two years. Those under 29 years old were more likely to have had a flare-up in that time (87%). We asked those who had had a flare-up how many times this had happened in the last two years.

	All %	UC %	CD %
One	24	26	24
Two	26	26	25
Three or more	38	37	37
Never in Remission	9	7	11

Symptoms that most affect people during a flare-up and during remission.

We asked people to think about the symptoms they experience both during a flare-up and during remission and rank the symptoms according to the impact they have on their life. The table shows the percentage of patients putting the symptom first, second, third etc. (16% did not rank their symptoms.)

Ulcerative Colitis

<i>During a flare-up</i>	First	Second	Third	Fourth	Fifth	No effect
	%	%	%	%	%	%
Urgency/diarrhoea	63	14	4	3	0	2
Incontinence	8	14	6	5	14	31
Pain	9	25	18	12	8	9
Tiredness	8	24	29	14	4	5
Weakness	2	7	20	29	12	13

<i>During remission</i>	First	Second	Third	Fourth	Fifth	No effect
	%	%	%	%	%	%
Urgency/diarrhoea	32	8	9	7	2	25
Incontinence	3	6	4	5	10	49
Pain	10	12	13	8	6	32
Tiredness	31	22	10	5	1	17
Weakness	2	19	14	11	4	32

Crohn's Disease

<i>During a flare-up.</i>	First	Second	Third	Fourth	Fifth	No effect
	%	%	%	%	%	%
Urgency/diarrhoea	43	21	9	7	1	4
Incontinence	5	7	6	7	18	33
Pain	30	23	14	10	3	3
Tiredness	10	27	31	14	3	1
Weakness	3	9	22	29	11	8

<i>During remission.</i>	First	Second	Third	Fourth	Fifth	No effect
	%	%	%	%	%	%
Urgency/diarrhoea	38	12	10	9	1	15
Incontinence	3	6	4	5	16	43
Pain	13	15	17	14	5	19
Tiredness	32	29	14	5	2	7
Weakness	3	19	20	14	5	21

The remainder of the survey asked questions to increase our understanding of the pain experienced by patients with Ulcerative Colitis or Crohn’s Disease. They were answered by all those in the survey who said they experience pain as one of the symptoms of their IBD - 82% of those with Crohn’s Disease and 73% of those who have Ulcerative Colitis.

Describing the pain they experience

The number of people answering these questions was 1942 (77% of the total sample). Some people experience more than one type of pain and may be included in the table under more than one heading. People were asked to describe how the pain felt, the intensity on a scale from 1 – 10 (*no pain – extreme pain*) and whether the pain was associated with eating or bowel movements.

	Abdominal Pain		Joint Pain		Back Pain	
<i>Number of people experiencing this type of pain.</i>	1712		1005		814	
	UC	CD	UC	CD	UC	CD
	781	899	426	572	353	450
<i>Percentage of people experiencing this type of pain.</i>	68%		40%		32%	
	63%	73%	34%	46%	28%	37%
	UC	CD	UC	CD	UC	CD
	%	%	%	%	%	%
<i>How pain relates to the IBD</i>						
Only during flare-ups	41	31	13	13	19	17
Have pain during remissions, but worse during flare-ups.	46	54	37	38	35	37
Even during remissions	10	14	47	47	40	41
Associated with eating?						
Yes	31	48	4	4	4	8
Associated with bowel motions?						
Yes	76	65	10	10	26	27
<i>Intensity of pain usually experienced: (% saying 7+)</i>	42	54	35	34	40	47
<i>Intensity of pain usually experienced: (% saying 5+)</i>	72	79	69	70	69	82
<i>How the pain feels</i>	Aching (51%)		Aching (79%)		Aching (76%)	
	Stabbing (47%) (UC 43%, CD 50%)		Constant (31%)		Deep-seated (31%)	
	Nauseating (40%) (UC 33%, CD 45%)		Dull (22%)		Constant (32%)	
	Deep-seated (34%)		Deep-seated (20%)		Dull (29%)	
	Constant (30%) (UC 24%, CD 35%)		Stabbing (17%)		Stabbing (16%)	
			Burning (13%)			

72% of the patients said that pain was always or sometimes an indication that a flare-up was occurring. 16% of those replying to the survey were experiencing a flare-up at the time.

Management of the Pain

67% of those who experienced pain had discussed this with their GP and about 60% with their gastroenterologist, smaller numbers had talked to other health professionals. Over 80% of these were described as responding sympathetically. 68% of patients received a prescription for medication to help their pain (UC 62%; CD 72%). The most commonly prescribed medicines were:

Paracetamol	44%
Neurofen or similar	24%
Anti-spasmodics	24%
Tramadol	11%

70% of people who received some form of medication said it helped to relieve their pain.

Only 17% of patients said their health professionals had suggested some other method of pain relief, but 37% had actually tried another approach themselves. The most commonly used ones, in order of frequency, were relaxation, physiotherapy, acupuncture, TENS machine, heat pads, reiki and reflexology.

The ongoing impact of pain on day-to-day life

Those patients who commented on this (43%) were asked to identify what they considered the most prominent pain associated with their IBD.

	Abdominal Pain		Joint Pain		Back Pain	
<i>Number of respondents answering yes and % of total respondents</i>	809 (32%) 377 432		237 (9%) 130 107		68 (3%) 36 32	
<i>How often the pain is experienced.</i>	Combined UC CD		Combined UC CD		Combined UC CD	
Constant or Daily	54% 55% 53%		75% 80% 70%		55% 60% 49%	
Weekly	24% 22% 25%		13% 10% 17%		22% 14% 32%	
<i>How intense is the pain today.</i>						
7+ on a scale of 1 - 10	11% 11% 13%		25% 24% 26%		11% 20% 6%	
5+ on a scale of 1 - 10	24% 23% 26%		45% 51% 39%		42% 51% 19%	
<i>How intense is the pain usually.</i>						
7+ on a scale of 1 - 10	39% 36% 42%		36% 38% 33%		46% 47% 45%	
5+ on a scale of 1 - 10	68% 68% 70%		71% 72% 71%		77% 75% 81%	
<i>What is your worst experience of pain.</i>						
9+ on a scale of 1 - 10	64% 53% 73%		52% 50% 51%		50% 55% 49%	
<i>How much pain interferes with your normal life.</i>						
7+ on a scale of 1 - 10	29%* 26% 31%		32% 34% 32%		32% 11% 14%	
* = 10% of total respondents						

The daily activities that people said were most affected are:

Those with abdominal pain:

Working 38%, sport 35%, holidays 26%, socializing 47%, sleeping 53%, housework 30%, taking the children to school 8%. 20% said that IBD pain interfered with their sleep on most nights.

30% of those whose pain interfered with their daily life had discussed this with a healthcare professional. 41% of these received any help in finding ways to lessen the impact of pain on their daily life.

31% of patients had been admitted to hospital at least twice because of their pain.

Those with joint pain:

Working 33%, sport 44%, holidays 19%, socializing 31%, sleeping 54%, housework 31%, taking the children to school 3%. About 22% said that IBD pain interfered with their sleep on most nights.

32% of those whose pain interfered with their daily life had discussed this with a healthcare professional. 45% of these received any help in finding ways to lessen the impact of pain on their daily life.

26% of patients had been admitted to hospital at least twice because of their pain.

Those with back pain:

Working 35%, sport 31%, holidays 21%, socializing 25%, sleeping 59%, housework 35%, taking the children to school 6%. 28% said that IBD pain interfered with their sleep on most nights.

32% of those whose pain interfered with their daily life had discussed this with a healthcare professional. 32% of these received any help in finding ways to lessen the impact of pain on their daily life.

30% of patients had been admitted to hospital at least twice because of their pain.

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