

Critical situations in daily life as experienced by patients with inflammatory bowel disease

Katarina Pihl Lesnovska, Gunilla Hollman Frisman,
Henrik Hjortswang and Sussanne Börjeson

Linköping University Post Print



N.B.: When citing this work, cite the original article.

Original Publication:

Katarina Pihl Lesnovska, Gunilla Hollman Frisman, Henrik Hjortswang and Sussanne Börjeson, Critical situations in daily life as experienced by patients with inflammatory bowel disease, 2015, Gastroenterology Nursing.

<http://dx.doi.org/10.1097/SGA.0000000000000211>

Copyright: Lippincott, Williams & Wilkins

<http://www.lww.com/>

Postprint available at: Linköping University Electronic Press

<http://urn.kb.se/resolve?urn=urn:nbn:se:liu:diva-126621>

Critical situations in daily life as experienced by patients with inflammatory bowel disease

Pihl Lesnovska, Katarina^{1,2}, Hollman Frisman, Gunilla^{2,4}, Hjortswang, Henrik^{1,3}, Börjeson, Susanne².

¹ Heart and Medicine Centre, Department of Gastroenterology and Hepatology, County Council of Östergötland, Linköping, Sweden.

² Department of Medical and Health Sciences, Linköping University, Sweden.

³ Heart and Medicine Centre, Department of Gastroenterology and Hepatology, Department of Clinical and Experimental Medicine, Linköping University, Sweden.

⁴ Anaesthetics, Operations and Speciality Surgery Centre, County Council of Östergötland, Linköping, Sweden

Corresponding author:

Katarina Pihl Lesnovska

Department of Gastroenterology

Linköping University Hospital

581 85 Linköping

Sweden

Email: katarina.pihl.lesnovska@lio.se

Tel: ++ 46 10 103 8133 Fax: ++ 46 10 103 3506

Critical situations in daily life as experienced by patients with inflammatory bowel disease

Abstract

1
2
3
4 Crohn's disease and ulcerative colitis, collectively known as inflammatory bowel disease
5 (IBD), are chronic and have a fluctuating clinical course that impacts on daily life. Daily life
6 with a chronic disease involves thinking and worrying about the limitations that it causes.
7
8 Knowledge about how patients who suffer from IBD manage critical incidents in daily life is
9 lacking.

10
11
12
13
14 The aim of the study was to describe how patients living with IBD experience critical inci-
15 dents in daily life in relation to their disease and symptoms.

16
17
18
19 Thirty adult patients were interviewed focusing on critical incidents in daily life. Data were
20 analyzed using the critical incident technique. The study comprised 224 critical incidents and
21 were grouped into 21 sub-categories and 5 categories; Losing bowel control, Having a body
22 that smells, Being unable to meet own and others' expectations, Not being believed or seen
23 and Experiencing frustration due to side-effects and ineffective treatment. These categories
24 formed one main area describing the overall result "The bowels rule life".
25
26
27
28

29
30
31 The uncertain nature of IBD created critical incidents in which the bowel ruled life, causing
32 patients to avoid social interaction. It also placed considerable demands on the family and
33 sometimes had a negative effect on the afflicted person's career.
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

Crohn's disease (CD) and ulcerative colitis (UC), collectively known as inflammatory bowel disease (IBD) (Loftus *et al.* 2002), are characterised by chronic inflammation of the gastrointestinal tract with periods of remission and relapse (Ekbom 2004, Loftus *et al.* 2002). Both CD and UC are associated with many disabling symptoms such as fatigue, diarrhoea and abdominal pain, leading to the need for maintenance medical treatment to control symptoms and remain in remission (Hjortswang *et al.* 2006, Van Assche *et al.* 2010).

Background

IBD involves limitations that preclude the ability to engage in normal daily activities (Peyrin-Biroulet *et al.* 2012, Peyrin-Biroulet *et al.* 2010). Living with a chronic disease affects psychological as well as social dimensions. IBD can lead to a wide range of psychological and interpersonal problems due to its unpredictable course (Casati & Toner 2000, Casati *et al.* 2000). The uncertainty of the symptoms creates situations that may be difficult for the patient to handle and involves constant consideration of the limitations imposed by the disease. If healthcare professionals are aware of the limitations, it can facilitate them to support patients to find strategies for handling such situations (Pihl Lesnovska K *et al.* 2010). Health related quality of life (HRQoL) in patients with IBD, as well as their limitations, worries and concerns have been thoroughly investigated [3, 5, 10]. However, there is a knowledge gap pertaining to situations that are the most critical for patients. Critical incidents related to living with a chronic disease and its symptoms have been studied in other chronic diseases and found to involve emotions such as isolation, shame, fear and worries about being a burden to family, friends and at work. They also involve relationships, such as becoming the focus of others' curiosity or the main topic of conversation at work or with friends (Sverker *et al.* 2005). There is a need for a deeper understanding of limitations and critical incidents in the daily life of patients with IBD.

The present study aimed to describe how patients with IBD experience critical incidents in daily life in relation to their disease and symptoms.

Methods

Design

The Critical Incident Technique (CIT) is a systematic method for eliciting information from respondents. It is based on factual reports of behaviour that make a significant contribution to the activity under investigation (Flanagan 1954). To be critical, an incident must constitute a major event of great importance to the person involved (Flanagan 1954). In a CIT study, the size of the sample is not determined by the number of participants but the number of incidents collected. If the situation is clearly defined, 50-100 incidents can be sufficient for qualitative analysis (Flanagan 1954, Norman *et al.* 1992). The number of critical incidents also depends on the complexity of the problem under study (Flanagan 1954, Norman *et al.* 1992). Norman *et al.* (Norman *et al.* 1992) suggested that the researcher should collect incidents until the last 100 fail to provide any new information. This approach is based on the researcher analysing and classifying the incidents as they are collected. Incidents can be collected by direct observation or retrospective accounts using a questionnaire or interviews. The CIT comprises five procedural steps:(1) determining the general aim of the activity; (2) developing plans and specifications for collecting factual incidents regarding the activity; (3) collecting the data (either through interview or written up by the observer); (4) analysing, as objectively as possible, and (5) interpreting and reporting on the requirements, particularly those which make a significant contribution to the activity. In the present study, an inductive approach with retrospective accounts and interviews was used as outlined by Flanagan and Norman (Flanagan 1954, Norman *et al.* 1992).

Data collection

Thirty patients, 14 men and 16 women, were strategically selected by means of quota sampling from an outpatient clinic in south-eastern Sweden, based on variation in age, sex, type of IBD, duration of IBD, relapse or remission and previous surgery (Table1). Quota sampling requires that representative individuals are chosen from a specific sub-group (Polit & Beck 2008). An information letter was sent to selected patients, explaining the purpose of the study, the meaning of informed consent, confidentiality and the right to withdraw from the study at any time without giving a reason. All the selected patients agreed to participate and returned their informed consent in a pre-paid envelope, after which they were contacted by telephone in order to arrange an appointment for the interview, which was conducted by the first author. Three of the 30 audio recorded interviews were held in the patient's home and 27 in a room at the hospital between July and December 2010 (Tong *et al.* 2007). The definition of a critical

1 incident was explained to the patients before the interviews as follows: a major event of great im-
2 portance, a situation that they still remembered due to its great significance for their daily life and way
3 of managing the disease (Flanagan 1954). The opening question was; can you please tell me about a
4 critical incident or situation in daily life related to your disease or symptoms that had consequences for
5 your life and way of managing the disease? Probing questions were used to elicit more details;
6
7 When/where did it occur? And how did you manage the situation? Two pilot interviews were performed,
8
9 which were included in the analysis, as the questions remained the same. Demographic data were col-
10 lected at the end of each interview. Three patients were born outside Sweden, five were on sick leave,
11 three unemployed, five had a retirement pension and seventeen were employed or studying. At the time
12 of the interview, four were in relapse and the rest in remission. The interviews took a mean time of 40
13 minutes (Tong *et al.* 2007). The text was transcribed verbatim from the audio recordings of the inter-
14 views. Eleven interviews were transcribed by the first author and 19 by an experienced secretary at the
15 Department of Gastroenterology. The first author reread all the interview transcripts to ensure that they
16 were correctly transcribed (Flanagan 1954, Tong *et al.* 2007). The first author, who has experience of
17 interview technique and qualitative methods, works at the hospital as a specialist IBD nurse but was not
18 involved in the care of the participants at the time of the interviews. The co-authors SB and GHF have
19 experience of qualitative research, while HH is a Medical Doctor in gastroenterology with long clinical
20 experience of caring for patients with IBD.
21
22
23
24
25
26
27
28
29
30
31
32
33

34 Analysis

35
36 The analysis process was inductive and started by reading each interview several times in order to be-
37 come familiar with the data. Critical incidents, which were the unit of analysis, were marked in the text;
38 a situation was defined as critical if it was related to the aim of the study and the interview question. A
39 total of 224 critical incidents were identified, systematically sorted in relation to content and divided into
40 groups. Critical incidents with a similar content were labelled and grouped into 21 sub-categories. At a
41 later stage the sub-categories were divided into 5 categories. In the final step the categories were la-
42 belled based on their comprehensive structure and main area. The analysis and classification were per-
43 formed on conclusion of the interviews and therefore it was not possible to determine whether saturation
44 was reached with the last 100 incidents. No new categories emerged in the analysis of the last 7 inter-
45 views. The first author read and collected critical incidents from all interviews and the co-authors each
46 read and collected incidents from six different interviews, a total of 18 interviews. To ensure validity the
47 authors had repeated discussions during the various steps of the analysis until consensus was achieved.
48 The co-authors served as independent judges and sorted the incidents into categories to ensure that they
49 were meaningful and consensus was reached (Norman *et al.* 1992).
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

1 Ethical considerations
2

3 The study was performed in accordance with the Declaration of Helsinki and approved by the Regional
4 Ethics Committee (WMADo. 2008). All patients were invited to contact the clinic after the interview if
5 they needed any kind of support.
6
7
8
9

10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

Results

1 This study captured 224 critical incidents experienced in daily life, which were divided into
2 21 sub-categories, 5 categories and one main area (Table 2). The main area was “The bowel
3 rules life”. The critical incidents described by the patients influenced them to a great extent in
4 their daily life.
5
6
7

Losing bowel control

10 This category concerned critical incidents when patients had been unable to reach the toilet in
11 time. They mentioned a wide variety of critical incidents at work, at school, at the cinema or
12 when travelling on public transport and being forced to get off the bus before reaching their
13 destination due to urgency. The incidents included being unable to reach the toilet in time
14 when playing with their children at the playground and their sense of embarrassment in front
15 of the other parents when obliged to return home to change. There were also incidents when
16 the patients had been at a restaurant and on the way home made a sudden movement that
17 caused them loss of bowel control, after which they had to walk home through the city with
18 soiled clothing visible to everyone or being unable to control the bowel in the car.
19
20
21
22
23
24
25
26
27
28
29

30 *“You can suddenly feel that you must go to the loo in some awkward situations. If you’re*
31 *stuck in traffic on the Essingeleden and feel that you have to go, it can be quite difficult.” (no.*
32 *5)*
33
34
35
36
37

38 The frequent loss of bowel control made it necessary for the patient to be aware of the loca-
39 tion of toilets or forced her/him to stay at home due to the uncertainty of finding a toilet in
40 time. Patients also described critical incidents that illustrated the importance of social support
41 in difficult situations.
42
43
44
45

46 *“I remember waking up one morning and having to go but did not reach the loo in time, alt-*
47 *hough I’m very lucky to have a really great partner. He’s not squeamish in any way, he has*
48 *put up with a great deal, because when it comes there’s quite a lot. You know, he puts on rub-*
49 *ber gloves and changes his clothes and then he wipes and....” (no. 29)*
50
51
52
53
54
55

56 Loss of bowel control was also described by patients with ostomy who experienced discom-
57 fort due to leakage of faeces, pus or blood when sun-bathing, while contact with water when
58
59
60
61
62
63
64
65

1 swimming weakened the adhesive property of the ostomy wafer, causing the ostomy appli-
2 ance to leak.
3

4
5 Having to sit for a long time on the toilet and not knowing when they would be ready or able
6 to leave was stressful, especially in public conveniences due to the fact that there is often a
7 queue. Some patients described leaving the toilet when they thought they were ready but were
8 often obliged to return after just a couple of minutes and the queue prevented them from
9 reaching the toilet in time. Critical situations were also related to the design of public toilets
10 with an air gap below the door so that the sound could be heard by those queuing outside. The
11 fact that the faeces had such a strong smell was also a reason for avoiding public toilets.
12
13
14
15
16
17

18
19
20 *“Because I sometimes have to sit in peace and quiet for five to ten minutes before it comes*
21 *and you can’t do that in a public toilet. I really have a problem with public toilets and of*
22 *course it restricts my life.” (no 24)*
23
24
25

26
27 The patients would like public toilets to have a washbasin in the cubicle. They also wanted a
28 lockable door with no air gap between the floor and door. The patients also described the in-
29 convenience of always needing to have coins available.
30
31

32 *Having a body that smells*

33
34
35
36 Patients described critical incidents where they felt that they smelled of faeces although they
37 washed and changed their underwear frequently, which made them feel unattractive, as did
38 leaking fistulas. The uncertainty concerning leakage forced the patients to adopt strategies
39 such as always wearing sanitary protection or carrying a change of underwear in a bag. Sani-
40 tary protection forced them to wear baggy clothes. Seton was another problem, as the rubber
41 bands irritated and chafed their skin and it was experienced as embarrassing in the context of
42 intimate moments with a partner.
43
44
45
46
47
48

49
50
51 *“For example, if you’re messy down there, because even if you make every effort to be clean,*
52 *it can come very quickly when you’re walking or such, it sometimes oozes out, really difficult,*
53 *then you go ugh ...if it oozes a lot when you are with a girl, then it’s not good, as you can*
54 *imagine!” (no. 19)*
55
56
57
58
59
60
61
62

1 The patients also reported that the frequent stools led to red and sore skin, which made them
2 feel ugly and unattractive when exposing their body. Other critical incidents were at the start
3 of a new relationship when the patients avoided going to the toilet because they felt that their
4 faeces had a bad smell during relapses. One young woman related that her boyfriend did not
5 have a window in the toilet and therefore she did not dare to visit him during a relapse be-
6 cause of the smell and the fact that she could not open a window to air the toilet. Another pa-
7 tient mentioned that relatives always noted that the faeces smelled in a certain way during a
8 relapse, which created a sense of being unattractive. One young man expressed that his stom-
9 ach rumbled so much when he went to the toilet that his friends put earplugs into their ears
10 and made fun of him, which made him avoid visiting the toilet when he was in the company
11 of others. Undergoing surgery and being fitted with a stoma was another critical situation that
12 made some patients feel unattractive. The critical incidents concerning the stoma were mainly
13 related to the implantation and surgery. After living with the stoma for a long time it normally
14 did not create concerns and the patient learned to manage the situation. Incidents mentioned
15 included sunbathing on the beach and going to a nightclub. These situations as well as being
16 naked in front of their partner made the patients feel unattractive.
17
18
19
20
21
22
23
24
25
26
27
28
29
30

31 *“It’s awfully hard; I didn’t exactly feel like a sex symbol when they fitted me with a stoma.”*
32 *(no. 17)*
33
34
35

36 *Being unable to meet own and others’ expectations*

37 The patients described critical incidents where their bowel problems affected their opportunity
38 to live up to or realise personal goals in life. These incidents were mostly related to their pro-
39 fessional life, such as being unable to work full-time or frequent sick leave resulting in lack of
40 promotion and no increase in salary. Relapse and/or symptom burden could also make them
41 turn down job opportunities and/or promotion.
42
43
44
45
46
47
48

49 *“But if you’re a manager and can’t work 100%, then you’re forced to leave and get another*
50 *job.” (no 2)*
51
52
53

54 Being unable to perform duties at work was another critical situation, for example if the
55 workplace did not have access to or their duties made it difficult to rush to a toilet. Some pa-
56 tients had public duties, while others had assignments where they lectured to large audiences
57 and in such situations reaching a toilet in time was critical. Situations that could be embarrass-
58
59
60
61
62
63
64
65

1 ing were having to rush to the toilet at an inconvenient time and being obliged to explain the
2 reason why. Some patients had to wear special clothing and protective equipment, for exam-
3 ple in the construction industry or forestry work, which made it difficult to reach a toilet in
4 time. Two incidents mentioned were the problem encountered by a logger in a high tree
5 equipped with protective gear and a building worker in a sky lift at a construction site.
6
7
8
9

10 For some patients a critical incident was when they had a relapse and had to phone their em-
11 ployer to request sick leave, as they were aware that it would be difficult to replace them be-
12 cause of their special duties. Critical incidents that caused a guilty conscience were common,
13 often related to their children, partners, friends, relatives or colleagues. One patient described
14 an incident when due to urgency she had to leave her children unattended in a shopping trol-
15 ley in the supermarket. There were also incidents where the patient had to be admitted to hos-
16 pital and forced to leave the children alone at home. Some described having to make unrea-
17 sonable demands on children or partners.
18
19
20
21
22
23
24
25

26
27 *“My absolutely worst memory was before the operation when my bowel was to be X-rayed*
28 *here at the hospital and I had to take an enema and just couldn't. I tried to do it lying on the*
29 *floor in the shower but had to ask my son to help me and he wasn't very old at the time and*
30 *all that came was blood, then I felt that I couldn't cope.” (no. 24)*
31
32
33
34
35

36 A few of the patients expressed feelings of making life difficult for their next of kin by not
37 reaching the toilet in time during a journey or in a shop. This meant that the whole family was
38 forced to interrupt the activity or outing while she/he changed her/his clothes, which created a
39 sense of guilt. Some of the patients chose not to tell their family how ill they were because
40 they did not wish to worry them.
41
42
43
44
45
46

47 Patients described critical incidents in relation to taking part in activities, such as playing with friends
48 and suddenly being forced to leave in the middle of the game. Such interruptions made the patients feel
49 alienated from their friends. Other critical incidents were being obliged to give up social activities which
50 had formed an important part of their life before the disease, for example skiing, travelling, attending
51 dinner parties and riding a motorcycle or simple activities considered normal by most people such as
52 having a coffee or shopping with friends. Some of the patients had strict routines that helped them to
53 manage daily life and when they deviated from these routines critical incidents occurred that made their
54 situation worse. It could for example involve adapting their food intake by not eating before leaving
55
56
57
58
59
60
61
62
63
64
65

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

home, taking note of what kind of food caused no ill-effects or planning where to sit in a theatre or cinema and personally booking the seats themselves. Strict routines and good social support helped some of the patients to remain active.

“It has happened that I have bought theatre tickets but was unable to go and that’s 300 Crowns down the drain.” (no. 21)

Another critical incident was being hospitalised, for example when having a subileus due to eating the wrong food. Critical incidents were also associated with physical symptoms such as episodes of stomach pain that led to difficulties completing or performing everyday tasks. The pain could occur suddenly and in a context that made them perceive it as critical. Being unable to do things that they felt they should and awareness of expectations from others were also perceived as problematic, such as planning activities in advance but lacking the energy to proceed due to symptoms related to the bowel as well as fatigue and joint pain.

Not being believed or seen

The experience of not being believed was described as not receiving concrete answers from healthcare professionals or the care they required.

“I had been left in a room and I pressed the alarm several times but nobody came, it was awful, ugh...the stoma kept filling up and at last somebody came and I asked can you change my stoma?, it’s about to burst, she just said ‘I belong to team A’! And then she left and found somebody else but it was too late, as it had already burst. It’s a shame because if the first person had changed it, that wouldn’t have happened... the care team should be irrelevant.” (no. 29)

Another experience of a critical incident was encountering incomprehension and not being believed by authorities such as employment services, insurance companies or daycare centres. One young man described how difficult it was to be both unemployed and ill because he was too sick to search for a job but too healthy not to be working. To ensure that all authorities received the correct health insurance certificate made a huge demand on and constituted a great effort for the patient.

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

“But the unemployment benefit office wasn’t pleased, they think it’s criminal and don’t understand what I suffer from, want to know why I don’t look for a job but am on unemployment benefit, it becomes a bit problematic.” (no. 10)

One patient related that a crèche demanded written proof that she/he was ill as the staff did not believe her/him. Another patient was criticised for leaving her child in the crèche for such a long time. Other critical incidents were the impression of not being believed when denied permission to use the toilet or being forced to explain why they urgently needed to use it. The fact that the disease was not visible also contributed to the sense of not being believed. One woman expressed that it would be easier to sit in a wheelchair because nobody would question her level of disability. Situations when the patient requested a specific seat at the theatre or cinema and felt obliged to explain the reason also created a feeling of not being believed. At times the patients started to question themselves because no one took their disease and symptoms seriously.

“I didn’t believe that I was very ill, as I didn’t get any help at first. So I don’t think I understood until they told me that I was to have an operation. I began to doubt myself, as nobody listened to me, but I gathered that having diarrhoea 15 times per day and a lot of blood isn’t good, although nobody else seemed to think so and thought that I was exaggerating. I just screamed.... I can’t live like this; I’m 25 years old... I don’t want to be a disease; I just want to be me.” (no. 26)

The sense of not being believed was reinforced by the absence of family visits when hospitalised. One young woman described not receiving any visits from her parents or siblings when in hospital due to the fact that the parents worked long hours and did not prioritise hospital visits.

Experiencing frustration due to side effects and ineffective treatment

Medication could also lead to side-effects, such as nausea, weight gain and hair loss, which caused critical incidents as well as frustration.

“And right now the problem is that the cortisone makes you swell up. In the face and a bit on your stomach and neck. I know it’s a lot of fluid and temporary but some days I feel very low.” (no. 26)

1 Patients who have lived with a complex disease for a long time and tried all available treatment includ-
2 ing surgery felt frustrated about the lack of improvement, which created a sense of hopelessness.
3

4
5 Some patients had experienced unpleasant treatment and medical examinations, for example colonosco-
6 pies and different kinds of x-ray. Patients described not only the difficulties associated with the exami-
7 nations but also the preparation beforehand, for example laxation prior to a colonoscopy when the pa-
8 tient had to drink 4 litres of laxatives. There were also incidents when the patient felt worried about the
9 treatment, for example in the case of pregnancy, when there was a fear that the treatment was not suffi-
10 cient in addition to concern about possible side-effects affecting the unborn baby.
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

Discussion

1 This study describes the complexity of living with a chronic disease such as IBD. A wide range of critical incidents were captured and what was very striking is that patients with IBD perceive disbelief on
2
3
4
5 the part of next of kin, the authorities and society in general. Patients who participated in the study considered that they were met by incomprehension and distrust because of societal norms and taboos. It was
6
7
8
9 also clear that the bowel rules life for patients living with IBD.

10
11
12 The loss of bowel control was of great concern for most of the patients in the study. They experienced
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65
The loss of bowel control was of great concern for most of the patients in the study. They experienced critical incidents in different contexts in their private and professional life when they were unable to reach the toilet in time. Other studies have revealed that it is not only the critical incident per se that causes concern but also worry about what it might lead to (Drossman *et al.* 1989, Stjernman *et al.* 2010). In previous research the top three concerns were having an ostomy, loss of energy and loss of bowel control. Four dimensions have been identified in descending order of concern: disease-related complications, daily life achievements, intimacy and stigmatisation (Stjernman *et al.* 2010). Loss of bowel control also involves leakage, odour and incontinence. Faecal incontinence has been studied previously (Norton *et al.* 2013) but is rarely described in relation to intimacy. In this study some patients related how they avoided intimacy and engaging in a partnership due to fear of leakage, incontinence and odour. Recent evidence suggests that up to 74% of patients with IBD experience faecal incontinence and not only during a relapse (Norton *et al.* 2013). In our study the loss of bowel control affected daily life and had a major impact on social and leisure activities. Similar results pertaining to limitations in everyday life as well as inability to act spontaneously have been presented in studies on patients who have an ostomy (Carlsson *et al.* 2001, Honkala & Berterö 2009, Pihl Lesnovska K *et al.* 2010).

41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65
Being unable to meet expectations concerned both one's own expectations and those of others. Societal norms for how a parent, sibling, partner and colleague should act contributed greatly to the expectations, but the disease made it difficult to live up to them. The question is whether these expectations were their own or placed on them by other people. The results also raise the issue of how a person's mental health is affected by the constant feeling of not living up to others' and own expectations. Our expectations may be influenced by our vision of what the future will be like, but whether this is the case in patients with IBD has, to the best of our knowledge, not yet been explored. Social and personal expectations can create security as well as a sense of not being good enough. Irrespective of whether or not these expectations are beyond our control or true in our own context, they can influence our inner world (Givón 1989, Gärdenfors 1994). The critical incidents made the patients either avoid social activities or plan them in advance. Previous studies have shown similar results among adolescents with IBD who

1 limited their social activities to those in which they had easy access to a toilet and where their absence
2 would not be problematic (Greenley *et al.* 2010, Mackner *et al.* 2012).
3
4

5 Not being believed or seen could be due to the fact that some patients lacked social support. One Ger-
6 man study revealed that in comparison with healthy controls, patients with IBD had a significantly
7 smaller social network, comprising fewer non-family members but deeper relationships with core family
8 members. They also reported a significantly smaller number of persons from whom they received social
9 support. Patients with active disease were generally less satisfied with the support received than those
10 whose disease was in remission (Sewitch *et al.* 2001). In our study ‘not being believed’ also involved
11 the experience of not receiving appropriate medical care. In the 2008 study by Rogala *et al.*, one quarter
12 of the patients with IBD in relapse reported not receiving care when necessary, in contrast to a commu-
13 nity sample, where only 12% mentioned this concern. However, the study showed that patients with IBD
14 in remission had a similar rate of unmet needs as the community sample (Rogala *et al.* 2008). When the
15 patients in our study experienced that they were not believed or seen, they withdrew from social life.
16 The extent of difficulty participating in social life is dependent on the activities the patient is used to
17 performing, but also on how easily she/he adapts to new circumstances caused by the disease and symp-
18 toms. Previous research found that the disease may contribute to major interference in terms of work
19 and daily activities (Rogala *et al.* 2008).
20
21
22
23
24
25
26
27
28
29
30
31
32

33
34 The first author conducted all interviews and ensured that the patients focused on the same issues to
35 guarantee validity since subtle changes in the wording of a question can lead to significant changes in
36 the response. The fact that all authors individually identified and categorised incidents increased validity
37 (Flanagan 1954, Norman *et al.* 1992). An accurate account of the data collection and analysis as well as
38 a description of the patients strengthened the reliability and validity of the study (Morse J M *et al.* 2002).
39 Validity was also strengthened by presenting relevant quotations from the transcribed text to further il-
40 lustrate the categories (Flanagan 1954, Morse J M *et al.* 2002, Norman *et al.* 1992). The data analysis
41 indicated that no further categories emerged after 23 interviews, which increased plausibility. One limi-
42 tation is that the method relies on the recollection of the patients and their ability to provide a detailed
43 account of a critical incident. The authors had confidence in the patients’ ability to tell their story, but it
44 should be borne in mind that there is always a possibility of misconception (Norman *et al.* 1992). The
45 categorisation of critical incidents is controversial and has been criticised for being subjective. Although
46 data can be categorised in more than one way, it is always possible to refer to the raw data (Norman *et*
47 *al.* 1992). The results of the present study are transferable to an IBD population in a western society,
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

although according to Flanagan (Flanagan 1954), it is always up to the reader to evaluate the transferability of the results.

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

Conclusion; implications for practice

1 The uncertain nature of IBD creates critical incidents that rule life in a way that causes patients to avoid
2 social interaction, place considerable demands on the family situation and may affect success in their
3 profession. Consequently, there is a need for greater awareness of the situation of patients with IBD.
4
5 Patients who live with IBD must be able to use public transportation, have access to public toilets and
6
7 manage to combine career and family life on equal terms with healthy individuals. When healthcare pro-
8
9 fessionals acquire this knowledge, one important task is advocacy to support and promote the interests
10
11 of patients with IBD. It is clear how the bowel ruled life for the patients in the study due to the complex-
12
13 ity of living with a chronic disease such as IBD.
14
15
16
17

Conflict of interest

18 We confirm that the article, data and tables have not been previously published and are not being con-
19
20 sidered for publication elsewhere.
21
22
23
24

Acknowledgements

25 The authors are grateful to the patients for their participation in this study and acknowledge funding
26
27 from the County Council of Östergötland.
28
29

30 *Contributors:* KPL (main author), GHF, SB and HH planned and designed the study. KPL organised and
31
32 carried out the interviews. KPL, GHF, SB and HHG analysed the data and drafted the paper.
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

References

- 1
2
3
4 Carlsson E, Berglund B & Nordgren S (2001): Living with an ostomy and short bowel
5 syndrome: practical aspects and impact on daily life. *J Wound Ostomy Continence*
6 *Nurs* **28**, 96-105.
- 7 Casati J & Toner BB (2000): Psychosocial aspects of inflammatory bowel disease. *Biomed*
8 *Pharmacother* **54**, 388-393.
- 9
10 Casati J, Toner BB, de Rooy EC, Drossman DA & Maunder RG (2000): Concerns of patients
11 with inflammatory bowel disease: a review of emerging themes. *Dig Dis Sci* **45**, 26-
12 31.
- 13 Drossman DA, Patrick DL, Mitchell CM, Zagami EA & Appelbaum MI (1989): Health-
14 related quality of life in inflammatory bowel disease. Functional status and patient
15 worries and concerns. *Dig Dis Sci* **34**, 1379-1386.
- 16 Ekbom A (2004): The epidemiology of IBD: a lot of data but little knowledge. How shall we
17 proceed? *Inflamm Bowel Dis* **10 Suppl 1**, S32-34.
- 18 Flanagan JC (1954): The critical incident technique. *Psychol Bull* **51**, 327-358.
- 19 Givón T (1989) *Mind, Code, and Context: Essays in Pragmatics*. Lawrence Erlbaum
20 Associates Hillsdale, NJ.
- 21
22 Greenley RN, Hommel KA, Nebel J, Raboin T, Li SH, Simpson P & Mackner L (2010): A
23 meta-analytic review of the psychosocial adjustment of youth with inflammatory
24 bowel disease. *J Pediatr Psychol* **35**, 857-869.
- 25 Gärdenfors P (1994) *The role of expectations in reasoning*. Springer Berlin Heidelberg.
- 26 Hjordswang H, Jarnerot G, Curman B, Sandberg-Gertzen H, Tysk C, Blomberg B, Almer S &
27 Strom M (2006): The Short Health Scale: a valid measure of subjective health in
28 ulcerative colitis. *Scand J Gastroenterol* **41**, 1196-1203.
- 29
30 Honkala S & Berterö C (2009): Living with an ostomy: Womens long term exeriecne *Vård i*
31 *Norden* **29**, 19-22.
- 32
33 Loftus EV, Jr., Schoenfeld P & Sandborn WJ (2002): The epidemiology and natural history of
34 Crohn's disease in population-based patient cohorts from North America: a systematic
35 review. *Aliment Pharmacol Ther* **16**, 51-60.
- 36
37 Mackner LM, Vannatta K & Crandall WV (2012): Gender differences in the social
38 functioning of adolescents with inflammatory bowel disease. *J Clin Psychol Med*
39 *Settings* **19**, 270-276.
- 40
41 Morse J M, Barret M, Mayan M, Olson K & Spiers J (2002): Verification strategies for
42 establishing reliability and validity in qualitative research. *International Journal of*
43 *Qualitative Methods* **1**, 13-22.
- 44
45 Norman IJ, Redfern SJ, Tomalin DA & Oliver S (1992): Developing Flanagan's critical
46 incident technique to elicit indicators of high and low quality nursing care from
47 patients and their nurses. *J Adv Nurs* **17**, 590-600.
- 48
49 Norton C, Dibley LB & Bassett P (2013): Faecal incontinence in inflammatory bowel disease:
50 Associations and effect on quality of life. *J Crohns Colitis* **7**, e302-311.
- 51
52 Peyrin-Biroulet L, Cieza A, Sandborn WJ, Coenen M, Chowers Y, Hibi T, Kostanjsek N,
53 Stucki G, Colombel JF & International Programme to Develop New Indexes for
54 Crohn's Disease g (2012): Development of the first disability index for inflammatory
55 bowel disease based on the international classification of functioning, disability and
56 health. *Gut* **61**, 241-247.
- 57
58 Peyrin-Biroulet L, Cieza A, Sandborn WJ, Kostanjsek N, Kamm MA, Hibi T, Lemann M,
59 Stucki G & Colombel JF (2010): Disability in inflammatory bowel diseases:
60 developing ICF Core Sets for patients with inflammatory bowel diseases based on the
61
62
63
64
65

International Classification of Functioning, Disability, and Health. *Inflamm Bowel Dis* **16**, 15-22.

1
2 Pihl Lesnovska K, Hjortswang H, A-C E & Hollman Frisman G (2010): Patients' perspective
3 of factors influencing quality of life while living with Crohn's Disease.
4 *Gastroenterology Nurs* **33**, 37-44.

5
6 Polit DF & Beck CT (2008) *Nursing Research generating and assessing evidence for nursing*
7 *practice*. Lippincott Williams & Wilkins

8 Rogala L, Miller N, Graff LA, Rawsthorne P, Clara I, Walker JR, Lix L, Ediger JP, McPhail
9 C & Bernstein CN (2008): Population-based controlled study of social support, self-
10 perceived stress, activity and work issues, and access to health care in inflammatory
11 bowel disease. *Inflamm Bowel Dis* **14**, 526-535.

12
13 Sewitch MJ, Abrahamowicz M, Bitton A, Daly D, Wild GE, Cohen A, Katz S, Szego PL &
14 Dobkin PL (2001): Psychological distress, social support, and disease activity in
15 patients with inflammatory bowel disease. *Am J Gastroenterol* **96**, 1470-1479.

16
17 Stjernman H, Tysk C, Almer S, Strom M & Hjortswang H (2010): Worries and concerns in a
18 large unselected cohort of patients with Crohn's disease. *Scand J Gastroenterol* **45**,
19 696-706.

20
21 Sverker A, Hensing G & Hallert C (2005): 'Controlled by food'- lived experiences of coeliac
22 disease. *J Hum Nutr Diet* **18**, 171-180.

23
24 Tong A, Sainsbury P & Craig J (2007): Consolidated criteria for reporting qualitative research
25 (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health*
26 *Care* **19**, 349-357.

27
28 Van Assche G, Dignass A, Reinisch W, van der Woude CJ, Sturm A, De Vos M, Guslandi M,
29 Oldenburg B, Dotan I, Marteau P, Ardizzone A, Baumgart DC, D'Haens G, Gionchetti
30 P, Portela F, Vucelic B, Soderholm J, Escher J, Koletzko S, Kolho KL, Lukas M,
31 Mottet C, Tilg H, Vermeire S, Carbonnel F, Cole A, Novacek G, Reinshagen M,
32 Tsianos E, Herrlinger K, Oldenburg B, Bouhnik Y, Kiesslich R, Stange E, Travis S,
33 Lindsay J, European Cs & Colitis O (2010): The second European evidence-based
34 Consensus on the diagnosis and management of Crohn's disease: Special situations. *J*
35 *Crohns Colitis* **4**, 63-101.

36
37 WMADo. H (2008) WMA Declaration of Helsinki - Ethical Principles for Medical Research
38 Involving Human Subjects. (Adopted by the 18th WMA General Assembly H,
39 Finland, June 1964 & and amended by the: 59th WMA General Assembly S, Korea,
40 October 2008. eds.).
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

Table 1 Background data of the participants

Variable	N = 30
Age range (M)	29-83 (M=45)
Sex	
Male	14
Female	16
Type of IBD	
Crohn´s Disease	18
Ulcerative Colitis	12
Duration of IBD	
0-5 years since diagnosis	8
>5-10 years since diagnosis	4
>10-15 years since diagnosis	6
>15 years or more since diagnosis	12
Medical maintenance treatment	29
Surgical procedures	11
Patients with a stoma	1
Patients with a temporary stoma	2

Table 2 Summary of the sub-categories, categories and main area describing critical incidents in daily life related to inflammatory bowel disease.

Main area	Category	Sub-category
The bowels rule life}	Losing control of the bowel	Being in a hurry and not reaching the toilet in time (39)
		Having to go to the toilet frequently (32)
		Having to sit on the toilet for a long time (8)
		Not having access to toilets with privacy (9)
	Having a body that smells	smelling of faeces (7)
		Receiving and living with a stoma (2)
		Leakage of stool, pus and blood (8)
	Being unable to meet own and others' expectations	Being hospitalized (2)
		Making unreasonable demands and exposing one's children to risks (5)
		Being forced to turn down job offers (7)
Unable to perform one's work (14)		
Being a burden to relatives/friends (11)		
Not being able to perform certain activities (19)		
Not being able to plan activities in advance and making definite plans (23)		
Not being believed or seen		Not receiving the care considered necessary (12)
	Being meet by incomprehension on the part of authorities (11)	
	Being denied use of a toilet (3)	
	Not being visited when hospitalized (2)	
Experiencing frustration due to side effects and ineffective treatment	Side effects of treatment (5)	
	Experiencing that treatment does not work (3)	
	Need to undergo extensive examinations (2)	

(Number of incidents in brackets, a total of 224 critical incidents.)

LWW Copyright and Disclosure Form

[Click here to download LWW Copyright and Disclosure Form: copyrightTransfer.pdf](#)

LWW Copyright and Disclosure Form

[Click here to download LWW Copyright and Disclosure Form: copyrightTransfer hhg.pdf](#)