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

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Abstract

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

The aim of the study was to describe how patients living with IBD experience critical incidents in daily life in relation to their disease and symptoms.

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

The uncertain nature of IBD created critical incidents in which the bowel ruled life, causing patients to avoid social interaction. It also placed considerable demands on the family and sometimes had a negative effect on the afflicted person’s career.
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.
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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 (Table 1). 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
incident was explained to the patients before the interviews as follows: a major event of great importance, a situation that they still remembered due to its great significance for their daily life and way of managing the disease (Flanagan 1954). The opening question was: can you please tell me about a critical incident or situation in daily life related to your disease or symptoms that had consequences for your life and way of managing the disease? Probing questions were used to elicit more details: When/where did it occur? And how did you manage the situation? Two pilot interviews were performed, which were included in the analysis, as the questions remained the same. Demographic data were collected at the end of each interview. Three patients were born outside Sweden, five were on sick leave, three unemployed, five had a retirement pension and seventeen were employed or studying. At the time of the interview, four were in relapse and the rest in remission. The interviews took a mean time of 40 minutes (Tong et al. 2007). The text was transcribed verbatim from the audio recordings of the interviews. Eleven interviews were transcribed by the first author and 19 by an experienced secretary at the Department of Gastroenterology. The first author reread all the interview transcripts to ensure that they were correctly transcribed (Flanagan 1954, Tong et al. 2007). The first author, who has experience of interview technique and qualitative methods, works at the hospital as a specialist IBD nurse but was not involved in the care of the participants at the time of the interviews. The co-authors SB and GHF have experience of qualitative research, while HH is a Medical Doctor in gastroenterology with long clinical experience of caring for patients with IBD.

Analysis
The analysis process was inductive and started by reading each interview several times in order to become familiar with the data. Critical incidents, which were the unit of analysis, were marked in the text; a situation was defined as critical if it was related to the aim of the study and the interview question. A total of 224 critical incidents were identified, systematically sorted in relation to content and divided into groups. Critical incidents with a similar content were labelled and grouped into 21 sub-categories. At a later stage the sub-categories were divided into 5 categories. In the final step the categories were labelled based on their comprehensive structure and main area. The analysis and classification were performed on conclusion of the interviews and therefore it was not possible to determine whether saturation was reached with the last 100 incidents. No new categories emerged in the analysis of the last 7 interviews. The first author read and collected critical incidents from all interviews and the co-authors each read and collected incidents from six different interviews, a total of 18 interviews. To ensure validity the authors had repeated discussions during the various steps of the analysis until consensus was achieved. The co-authors served as independent judges and sorted the incidents into categories to ensure that they were meaningful and consensus was reached (Norman et al. 1992).
Ethical considerations

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

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

Losing bowel control

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

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

The frequent loss of bowel control made it necessary for the patient to be aware of the location of toilets or forced her/him to stay at home due to the uncertainty of finding a toilet in time. Patients also described critical incidents that illustrated the importance of social support in difficult situations.

“I remember waking up one morning and having to go but did not reach the loo in time, although I’m very lucky to have a really great partner. He’s not squeamish in any way, he has put up with a great deal, because when it comes there’s quite a lot. You know, he puts on rubber gloves and changes his clothes and then he wipes and…. ” (no. 29)

Loss of bowel control was also described by patients with ostomy who experienced discomfort due to leakage of faeces, pus or blood when sun-bathing, while contact with water when
swimming weakened the adhesive property of the ostomy wafer, causing the ostomy appliance to leak.

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

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

The patients would like public toilets to have a washbasin in the cubicle. They also wanted a lockable door with no air gap between the floor and door. The patients also described the inconvenience of always needing to have coins available.

**Having a body that smells**

Patients described critical incidents where they felt that they smelled of faeces although they washed and changed their underwear frequently, which made them feel unattractive, as did leaking fistulas. The uncertainty concerning leakage forced the patients to adopt strategies such as always wearing sanitary protection or carrying a change of underwear in a bag. Sanitary protection forced them to wear baggy clothes. Seton was another problem, as the rubber bands irritated and chafed their skin and it was experienced as embarrassing in the context of intimate moments with a partner.

“For example, if you’re messy down there, because even if you make every effort to be clean, it can come very quickly when you’re walking or such, it sometimes oozes out, really difficult, then you go ugh …if it oozes a lot when you are with a girl, then it’s not good, as you can imagine!” (no. 19)
The patients also reported that the frequent stools led to red and sore skin, which made them feel ugly and unattractive when exposing their body. Other critical incidents were at the start of a new relationship when the patients avoided going to the toilet because they felt that their faeces had a bad smell during relapses. One young woman related that her boyfriend did not have a window in the toilet and therefore she did not dare to visit him during a relapse because of the smell and the fact that she could not open a window to air the toilet. Another patient mentioned that relatives always noted that the faeces smelled in a certain way during a relapse, which created a sense of being unattractive. One young man expressed that his stomach rumbled so much when he went to the toilet that his friends put earplugs in to their ears and made fun of him, which made him avoid visiting the toilet when he was in the company of others. Undergoing surgery and being fitted with a stoma was another critical situation that made some patients feel unattractive. The critical incidents concerning the stoma were mainly related to the implantation and surgery. After living with the stoma for a long time it normally did not create concerns and the patient learned to manage the situation. Incidents mentioned included sunbathing on the beach and going to a nightclub. These situations as well as being naked in front of their partner made the patients feel unattractive.

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

Being unable to meet own and others’ expectations
The patients described critical incidents where their bowel problems affected their opportunity to live up to or realise personal goals in life. These incidents were mostly related to their professional life, such as being unable to work full-time or frequent sick leave resulting in lack of promotion and no increase in salary. Relapse and/or symptom burden could also make them turn down job opportunities and/or promotion.

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

Being unable to perform duties at work was another critical situation, for example if the workplace did not have access to or their duties made it difficult to rush to a toilet. Some patients had public duties, while others had assignments where they lectured to large audiences and in such situations reaching a toilet in time was critical. Situations that could be embarrass-
ing were having to rush to the toilet at an inconvenient time and being obliged to explain the reason why. Some patients had to wear special clothing and protective equipment, for example in the construction industry or forestry work, which made it difficult to reach a toilet in time. Two incidents mentioned were the problem encountered by a logger in a high tree equipped with protective gear and a building worker in a sky lift at a construction site.

For some patients a critical incident was when they had a relapse and had to phone their employer to request sick leave, as they were aware that it would be difficult to replace them because of their special duties. Critical incidents that caused a guilty conscience were common, often related to their children, partners, friends, relatives or colleagues. One patient described an incident when due to urgency she had to leave her children unattended in a shopping trolley in the supermarket. There were also incidents where the patient had to be admitted to hospital and forced to leave the children alone at home. Some described having to make unreasonable demands on children or partners.

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

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

Patients described critical incidents in relation to taking part in activities, such as playing with friends and suddenly being forced to leave in the middle of the game. Such interruptions made the patients feel alienated from their friends. Other critical incidents were being obliged to give up social activities which had formed an important part of their life before the disease, for example skiing, travelling, attending dinner parties and riding a motorcycle or simple activities considered normal by most people such as having a coffee or shopping with friends. Some of the patients had strict routines that helped them to manage daily life and when they deviated from these routines critical incidents occurred that made their situation worse. It could for example involve adapting their food intake by not eating before leaving
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.
“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)
Patients who have lived with a complex disease for a long time and tried all available treatment including surgery felt frustrated about the lack of improvement, which created a sense of hopelessness.

Some patients had experienced unpleasant treatment and medical examinations, for example colonoscopies and different kinds of x-ray. Patients described not only the difficulties associated with the examinations but also the preparation beforehand, for example laxation prior to a colonoscopy when the patient had to drink 4 litres of laxatives. There were also incidents when the patient felt worried about the treatment, for example in the case of pregnancy, when there was a fear that the treatment was not sufficient in addition to concern about possible side-effects affecting the unborn baby.
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Discussion

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 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 also clear that the bowel rules life for patients living with IBD.

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).

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

Not being believed or seen could be due to the fact that some patients lacked social support. One German study revealed that in comparison with healthy controls, patients with IBD had a significantly smaller social network, comprising fewer non-family members but deeper relationships with core family members. They also reported a significantly smaller number of persons from whom they received social support. Patients with active disease were generally less satisfied with the support received than those whose disease was in remission (Sewitch et al. 2001). In our study ‘not being believed’ also involved the experience of not receiving appropriate medical care. In the 2008 study by Rogala et al., one quarter of the patients with IBD in relapse reported not receiving care when necessary, in contrast to a community sample, where only 12% mentioned this concern. However, the study showed that patients with IBD in remission had a similar rate of unmet needs as the community sample (Rogala et al. 2008). When the patients in our study experienced that they were not believed or seen, they withdrew from social life. The extent of difficulty participating in social life is dependent on the activities the patient is used to performing, but also on how easily she/he adapts to new circumstances caused by the disease and symptoms. Previous research found that the disease may contribute to major interference in terms of work and daily activities (Rogala et al. 2008).

The first author conducted all interviews and ensured that the patients focused on the same issues to guarantee validity since subtle changes in the wording of a question can lead to significant changes in the response. The fact that all authors individually identified and categorised incidents increased validity (Flanagan 1954, Norman et al. 1992). An accurate account of the data collection and analysis as well as a description of the patients strengthened the reliability and validity of the study (Morse J M et al. 2002). Validity was also strengthened by presenting relevant quotations from the transcribed text to further illustrate the categories (Flanagan 1954, Morse J M et al. 2002, Norman et al. 1992). The data analysis indicated that no further categories emerged after 23 interviews, which increased plausibility. One limitation is that the method relies on the recollection of the patients and their ability to provide a detailed account of a critical incident. The authors had confidence in the patients’ ability to tell their story, but it should be borne in mind that there is always a possibility of misconception (Norman et al. 1992). The categorisation of critical incidents is controversial and has been criticised for being subjective. Although data can be categorised in more than one way, it is always possible to refer to the raw data (Norman et al. 1992). The results of the present study are transferable to an IBD population in a western society,
although according to Flanagan (Flanagan 1954), it is always up to the reader to evaluate the transferability of the results.
Conclusion; implications for practice

The uncertain nature of IBD creates critical incidents that rule life in a way that causes patients to avoid social interaction, place considerable demands on the family situation and may affect success in their profession. Consequently, there is a need for greater awareness of the situation of patients with IBD. Patients who live with IBD must be able to use public transportation, have access to public toilets and manage to combine career and family life on equal terms with healthy individuals. When healthcare professionals acquire this knowledge, one important task is advocacy to support and promote the interests of patients with IBD. It is clear how the bowel ruled life for the patients in the study due to the complexity of living with a chronic disease such as IBD.

Conflict of interest

We confirm that the article, data and tables have not been previously published and are not being considered for publication elsewhere.

Acknowledgements

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Contributors: KPL (main author), GHF, SB and HH planned and designed the study. KPL organised and carried out the interviews. KPL, GHF, SB and HHG analysed the data and drafted the paper.
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<table>
<thead>
<tr>
<th>Variable</th>
<th>N = 30</th>
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<tbody>
<tr>
<td>Age range (M)</td>
<td>29-83 (M=45)</td>
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<tr>
<td>Sex</td>
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<tr>
<td>Male</td>
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</tr>
<tr>
<td>Female</td>
<td>16</td>
</tr>
<tr>
<td>Type of IBD</td>
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<td>Crohn’s Disease</td>
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<td>Ulcerative Colitis</td>
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<tr>
<td>Duration of IBD</td>
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<td>&gt;10-15 years since diagnosis</td>
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<td>&gt;15 years or more since diagnosis</td>
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<tr>
<td>Medical maintenance treatment</td>
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<tr>
<td>Surgical procedures</td>
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<tr>
<td>Patients with a stoma</td>
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<tr>
<td>Patients with a temporary stoma</td>
<td>2</td>
</tr>
</tbody>
</table>
Table 2  Summary of the sub-categories, categories and main area describing critical incidents in daily life related to inflammatory bowel disease.

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

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