



Katarina Pihl Lesnovska, MSc, RN
Gunilla Hollman Frisman, PhD, RN
Henrik Hjortswang, PhD, MD
Sussanne Börjeson, PhD, RN

Critical Situations in Daily Life as Experienced by Patients With Inflammatory Bowel Disease

ABSTRACT

Crohn disease and ulcerative colitis, collectively known as inflammatory bowel disease (IBD), are chronic and have a fluctuating clinical course that impacts daily life. Daily life with a chronic disease involves thinking and worrying about the limitations that chronic disease 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 was grouped into 21 subcategories 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 disease and ulcerative colitis, collectively known as inflammatory bowel disease (IBD) (Loftus, Schoenfeld, & Sandborn, 2002), are characterized by chronic inflammation of the gastrointestinal tract with periods of remission and relapse (Ekbohm, 2004; Loftus et al.,

2002). Both Crohn disease and ulcerative colitis are associated with many disabling symptoms such as fatigue, diarrhea, 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).

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About the authors: Katarina Pihl Lesnovska, MSc, RN, is PhD Student, Heart and Medicine Centre, Department of Gastroenterology and Hepatology, County Council of Östergötland, and Department of Medical and Health Sciences, Linköping University, Linköping, Sweden.

Gunilla Hollman Frisman, PhD, RN, is Associate Professor, Department of Medical and Health Sciences, Linköping University, and Anaesthetics, Operations and Speciality Surgery Centre, County Council of Östergötland, Linköping, Sweden.

Henrik Hjortswang, PhD, MD, is Associate Professor, Heart and Medicine Centre, Department of Gastroenterology and Hepatology, County Council of Östergötland, and Department of Clinical and Experimental Medicine, Linköping University, Linköping, Sweden.

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Sussanne Börjeson, PhD, RN, Associate Professor, Department of Medical and Health Sciences, Linköping University, Sweden.

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Correspondence to: Katarina Pihl Lesnovska, MSc, RN, Department of Gastroenterology, Linköping University Hospital, 581 85 Linköping, Sweden (katarina.pihl.lesnovska@lio.se).

Background

IBD involves limitations that preclude the ability to engage in normal daily activities (Peyrin-Biroulet et al., 2010, 2012). 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, Toner, de Rooy, Drossman, & Maunder, 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, awareness can facilitate them to support patients to find strategies for handling such situations (Pihl Lesnovska, Hjortswang, Ek, & Frisman, 2010).

Health-related quality of life in patients with IBD, as well as their limitations, worries, and concerns, have been thoroughly investigated (Stjernman, Tysk, Almer, Strom, & Hjortswang, 2010; Lesnovska et al., 2010). 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 were found to involve emotions such as isolation, shame, fear, and worries about being a burden to family, friends, and at work. Critical incidents also involve relationships, such as becoming the focus of others' curiosity or the main topic of conversation at work or with friends (Sverker, Hensing, & Hallert, 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 behavior 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, Redfern, Tomalin, & Oliver, 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 analyzing 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) analyzing, 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 informants, 14 men and 16 women, were strategically selected by means of quota sampling from an outpatient clinic in southeastern Sweden based on variation in age, gender, type of IBD, duration of IBD, relapse or remission, and previous surgery (Table 1). Quota sampling requires that representative individuals

TABLE 1. Background Data of the Informants

Variable	<i>n</i> = 30
Age range (<i>M</i>)	29–83 (45)
Gender	
Male	14
Female	16
Type of IBD	
Crohn 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 since diagnosis	12
Medical maintenance treatment	29
Surgical procedures	11
Patients with a stoma	1
Patients with a temporary stoma	2
<i>Note.</i> IBD = inflammatory bowel disease.	

are chosen from a specific subgroup (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 prepaid 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 informant's home and 27 in a room at the hospital between July and December 2010.

The definition of a critical incident was explained to the informants 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 informants were born outside Sweden, five were on sick leave, three unemployed, five had a retirement pension, and 17 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.

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 coauthors SB and GHF have experience with qualitative research, whereas HH is a medical doctor in gastroenterology with extensive 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 labeled and grouped into 21 subcategories. At a later stage, the subcategories were divided into five categories. In the final step, the categories were labeled 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 seven 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 coauthors served as independent judges and sorted the incidents into categories to ensure that they were meaningful and consensus was reached as recommended by 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 informants were invited to contact the clinic after the interview if they needed any kind of support.

Results

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

Losing Bowel Control

This category concerned critical incidents when informants had been unable to reach the toilet in time. They mentioned a wide variety of critical incidents at work, school, 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 informants had been at a restaurant and on the way home, made a sudden movement that caused them loss of bowel control, after

TABLE 2. Summary of the Subcategories, Categories, and Main Area Describing Critical Incidents in Daily Life Related to Inflammatory Bowel Disease^a

Main Area	Category	Subcategory
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 feces (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 met 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)

^aNumber of incidents in parentheses, a total of 224 critical incidents.

which they had to walk home through the city with soiled clothing visible to everyone or were unable to control their 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 informant 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. Informants 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 informants with ostomy who experienced discomfort due to leakage of feces, pus, or blood when sunbathing when

contact with water while 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 because there is often a queue. Some informants 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 feces 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 informants 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 to access a public toilet.

Having a Body That Smells

Informants described critical incidents where they felt that they smelled of feces (although they washed and changed their underwear frequently) which made them feel unattractive, as did leaking fistulas. The uncertainty concerning leakage forced the informants 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. The presence of a seton stitch, a piece of surgical thread that is left in a fistula tract to keep the tract open, 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 informants 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 informants avoided going to the toilet because they felt that their feces 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 informant mentioned that relatives always noted that the feces 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 into 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 informants 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 informant 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 informants 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 informants described critical incidents where their bowel problems affected their opportunity to live up to or realize 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 or their duties made it difficult to rush to a toilet. Some informants had public duties, whereas others had assignments where they lectured to large audiences and in such situations reaching a toilet in time was critical. Situations that could be embarrassing were having to rush to the toilet at an inconvenient time and being obliged to explain the reason why. Some informants 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 informants, 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 informant 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 informant had to be admitted to a 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 informants 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 informants chose not to tell their family how ill they were because they did not wish to worry them.

Informants 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 informants 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 informants 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 theater or cinema and personally booking the seats themselves. Strict routines and good social support helped some of the informants 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 hospitalized; 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 centers. 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 informant.

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 informant related that a daycare center demanded written proof that she/he was ill as the staff did not believe her/him. Another informant was criticized for leaving her child in the daycare 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 informant requested a specific seat at the theater or cinema and felt obliged to explain the reason also created a feeling of not being believed. At times, the informants 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 hospitalized. One young woman described not receiving any visits from

her parents or siblings when in hospital because the parents worked long hours and did not prioritize 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)

Informants 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 informants had experienced unpleasant treatment and medical examinations; for example, colonoscopies and different kinds of x-ray. Informants described not only the difficulties associated with the examinations, but also the preparation beforehand; for example, bowel cleansing before a colonoscopy when the informant had to drink 4 L of laxatives. There were also incidents when the informant 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.

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 informants with IBD perceived disbelief on the part of next of kin, the authorities, and society in general. Informants 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 informants 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, Patrick, Mitchell, Zagami, & Appelbaum, 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 stigmatization (Stjernman et al., 2010).

Loss of bowel control also involves leakage, odor, and incontinence. Fecal incontinence has been studied previously (Norton, Dibley, & Bassett, 2013), but is rarely described in relation to intimacy. In this study, some informants related how they avoided intimacy and engaging in a partnership due to fear of leakage, incontinence, and odor. Recent evidence suggests that up to 74% of patients with IBD experience fecal 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, Berglund, & Nordgren, 2001; Honkala & Berterö, 2009; Pihl Lesnovska 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 these expectations. The question is whether these expectations were the informant's 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 their 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 (Gärdenfors, 1994; Givón, 1989). The critical incidents made the informants 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, Vannatta, & Crandall, 2012).

Not being believed or seen could be because some informants lacked social support. One German study revealed that in comparison with healthy controls, patients with IBD had a significantly smaller social network, comprising fewer nonfamily 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 informants 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 individual 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 informants focused on the same issues to guarantee validity because subtle changes in the wording of a question can lead to significant changes in the response. The fact that all authors individually identified and categorized incidents contributed increased validity (Flanagan, 1954; Norman et al., 1992). An accurate account of the data collection and analysis as well as a description of the informants strengthened the reliability and validity of the study based on recommendations by Morse, Barret, Mayan, Olson, and Spiers (2002). Validity was also strengthened by presenting relevant quotations from the transcribed text to further illustrate the categories (Flanagan, 1954; Morse et al., 2002; Norman et al., 1992). The data analysis indicated that no further categories emerged after 23 interviews, which increased plausibility.

Limitations

One limitation is that the method relies on the recollection of the informants and their ability to provide a detailed account of a critical incident. The authors had confidence in the informants’ 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 categorization of critical incidents is controversial and has been criticized for being subjective. Although data can be categorized 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 (1954), it is always up to the reader to evaluate the transferability of the results.

Conclusions

The uncertain nature of IBD creates critical incidents that rule life in a way that causes individuals 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 individuals with IBD. Individuals 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 health-care professionals acquire this knowledge, one important task is advocacy to support and promote the interests of persons with IBD. It is clear how the bowel ruled life for the informants in the study due to the complexity of living with a chronic disease such as IBD. ❁

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