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Self-Care Among Patients With Inflammatory Bowel Disease

An Interview Study

ABSTRACT

Inflammatory bowel disease (IBD) is a chronic disease of unknown etiology. The disease occurs early in life and the burden of symptoms is significant. Patients need to perform self-care to handle their symptoms, but knowledge about what kind of self-care patients do is limited and these individuals need to learn how to manage the symptoms that arise. The aim of this study was to explore self-care among patients with IBD. Twenty adult patients with IBD, 25–66 years of age, were interviewed. Data were analyzed by performing a qualitative content analysis. Four categories with 10 subcategories emerged from the analysis of the interviews. The self-care patients perform consists of symptom recognition (subcategories: physiological sensations and psychological sensations), handling of symptoms (subcategories: adapting the diet, using medical treatment, stress management, and using complementary alternative medicine), planning life (subcategories: planning for when to do activities and when to refrain from activities), and seeking new options (subcategories: seeking knowledge and personal contacts). Self-care consists of symptom recognition, handling life through planning, and accommodating the existing situation with the ultimate goal of maintaining well-being. Being one step ahead facilitates living with IBD. A decision to actively participate in care of a chronic illness is a prerequisite for self-care. Healthcare professionals must consider patients' potential for and desire for self-care when giving advice on self-care activities. Doing so may help people better cope with IBD.

Inflammatory bowel disease (IBD) is an umbrella term for ulcerative colitis (UC) and Crohn disease (CD). Inflammatory bowel disease is a lifelong medical condition, usually with early onset in life, age 15–35 years, and still without any clear etiology (Dignass et al., 2010, Dignass, Eliakim, et al., 2012; O'Connor et al., 2013). The prevalence for IBD in Europe is approximately 2.5–3 million people (Burisch, Jess, Martinato, & Lakatos,

2013). The incidence of UC has remained relatively stable, except for Southern Europe, where the incidence of CD has increased in recent years (Barlow, Cooke, Mulligan, Beck, & Newman, 2010).

Background

Symptoms are the primary contributor to life constraints for patients with IBD (Hjortswang et al., 2003;

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U.L.W. (principal author), P.Y.-U., H.H., B.R., and G.H.F. planned and designed the study. U.L.W. organized and carried out the interviews. U.L.W., P.Y.-U., H.H., and G.H.F. analyzed the data, and all authors drafted the paper. All authors contributed to revisions and the final version of the manuscript.

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Lesnovska, Börjeson, Hjortswang, & Frisman, 2013; Pihl-Lesnovska, Hjortswang, Ek, & Frisman, 2010; Stjernman, Tysk, Almer, Ström, & Hjortswang, 2010). The primary symptoms of pain and frequent diarrhea cause life restriction and anxiety about the future for patients with IBD, which affect their psychological and social dimensions of life (Barlow et al., 2010; Dignass et al., 2010; Farrell & Savage, 2012). Medical and surgical treatments relieve symptoms, but patients must learn to manage their illness through self-care (Barlow et al., 2010; Van Assche et al., 2013).

Nordic studies have shown a significant increase in sickness and disability among patients with CD compared with the general population (Mesterton et al., 2009). Women feel worse and have higher rates of sickness, disability pension, and single living (Stjernman, Tysk, Almer, Ström, & Hjortswang, 2011). For CD, health and absenteeism costs are double those of UC, despite 50% lower prevalence. More than 60% of these costs are related to loss of work productivity (Mesterton et al., 2009).

Self-care is essential to improve outcomes in patients with chronic diseases (Riegel, Lee, Dickson, & Medscape, 2011). Self-care is defined as an active process to maintain and promote health for patients with IBD in the context of living with a chronic disease (Riegel, Jaarsma, & Strömberg, 2012). We have shown previously that quality of life is impaired and knowledge needs are great in patients with IBD, as symptoms restrict their participation in social life (Lesnovska et al., 2014; Pihl-Lesnovska et al., 2010; Stjernman et al., 2010). Patients with IBD have difficulties evaluating their symptoms and making decisions about self-care actions (Lesnovska et al., 2014). Earlier studies of self-care for patients with IBD focused on the environmental factors that can trigger disease exacerbations and provoke relapse in patients with IBD. Furthermore, medical treatment for maintenance of remission, adherence to treatments, psychosocial factors, diet therapy, and probiotics are studied (Dignass et al., 2010; Dignass, Lindsay, et al., 2012).

It is important for healthcare professionals to identify individual experiences and provide information and support so patients are able to manage their daily lives to maintain work, social life, and economic independence (Riegel et al., 2012). Knowledge about the self-care of patients with IBD is limited (Barlow et al., 2010; Dignass et al., 2010; Molodecky et al., 2012). The purpose of this study was to explore self-care among patients with IBD.

Methods

Design and Sample

As little is known about self-care of IBD patients, a qualitative inductive descriptive design was chosen to explore self-care among patients with IBD. A purposive

sampling plan was used and patients ($n = 20$) with IBD were selected from two hospitals in south-eastern Sweden. Inclusion criteria specified enrollment of adults older than 18 years with a confirmed diagnosis of IBD. Exclusion criteria were patients with IBD who have undergone surgery within the last 6 months, patients with another severe symptomatic chronic disease, and those without proficiency in the Swedish language. Maximum variation sampling in age, gender, and duration of IBD was used (Hsieh & Shannon, 2005).

Patients were recruited with support from a physician at each hospital who confirmed that the patients had IBD and were eligible for the study. Eligible patients received an information letter containing a description of the study, the consent form, and a postage-paid return envelope. Patients who agreed to participate signed and returned the consent form by mail. These willing individuals were contacted by telephone to make an appointment for an interview. Information about the study was repeated before the interviews to ensure that participants were fully informed and consenting. Confidentiality throughout the study was ensured by the principal investigator.

Data Collection

The interviews took place from June 2012 to May 2013. All interviews were performed by the first author, a nurse who was not involved in the care of the informants. Three pilot interviews were performed and an additional question was added after these pilot interviews. As changes were minor, the pilot interviews were included in the analysis. The interviews were performed in a location chosen by the informant: the informant's home ($n = 8$), a room close to the hospital ($n = 8$), or the patient's work environment ($n = 3$). One telephone interview was conducted on the basis of the patient's desire to participate, but symptoms of fatigue and frequent diarrhea prevented an in-person session.

Interviews were guided with the following questions: Please tell me what self-care means to you? Tell me what you do to influence your disease in order to feel well? Tell me what you particularly attend to related to your disease and tell me what you do to manage symptoms of your disease. The interviews lasted between 20 and 50 minutes. All interviews were digitally recorded and verbally transcribed by the first author (Hsieh & Shannon, 2005). Demographic characteristics such as age, gender, diagnosis, education level, occupation, duration of IBD, and if the patient was in remission or relapse were collected after the interview if not revealed during the interviews. The demographic characteristics of informants are shown in Table 1.

TABLE 1. Demographic Characteristics Based on the Informants ($n = 20$)

| | <i>n</i> | Median | Range |
|-------------------------------------|----------|--------|-------|
| Age (years) | 20 | 43 | 25–66 |
| Gender | | | |
| Male | 10 | | |
| Female | 10 | | |
| Marital status | | | |
| Married/cohabitating | 17 | | |
| Single | 3 | | |
| Education level | | | |
| Compulsory school (<9 years) | 3 | | |
| Upper secondary school (9–12 years) | 9 | | |
| University (>12 years) | 8 | | |
| Residence | | | |
| City | 9 | | |
| Rural area | 11 | | |
| Occupational status | | | |
| Full-time work | 9 | | |
| Part-time work | 6 | | |
| Sick leave | 2 | | |
| Unemployed | 2 | | |
| Retired | 1 | | |
| Diagnosis | | | |
| Crohn disease | 12 | | |
| Ulcerative colitis | 8 | | |
| Duration of disease (years) | | 11 | 1–46 |
| Surgery | 7 | | |
| Remission | 17 | | |
| Medical treatment | 19 | | |

Analysis

Qualitative research is a flexible method for developing knowledge of the human experience of health and illness. Conventional content analysis was chosen to explore self-care as the phenomenon of interest in patients with IBD. Conventional content analysis provides a subjective interpretation of the content of the text through a systematic classification process of coding and identifying patterns (Hsieh & Shannon, 2005). In the first step, the authors read the transcript interviews repeatedly to immerse themselves in the text and

to get a sense of the whole. In the second step, the text was read word by word to derive codes. The third step involved highlighting exact words or phrases from the text to capture key thoughts or concepts. In the fourth step, these exact words or phrases were placed in an excel data file and codes were derived to record initial impressions about the text. Furthermore, in the fifth step, the first author and the coauthor independently sorted the codes derived into categories and grouped conceptually linked words or phrases within these categories. The authors then met several times to discuss the findings and resolve differences in coding and category development. In the last step, definitions for codes, subcategories, and each category were developed. These definitions were discussed until consensus was reached (Hsieh & Shannon, 2005). The paper was drafted by all authors. The analysis process is described in Table 2.

Ethical Considerations

The study was conducted in accordance with the “Ethical Principles for Medical Research Involving Human Subjects,” Declaration of Helsinki, by the 18th World Medical Assembly (WMA) in Helsinki, Finland, in 1964, revised in 2008 (WMA, 2013). Ethical permission for data collection and analysis in south-eastern Sweden was approved by the Regional Ethical Review Board, Dnr: 2011/288-32 and Dnr: 2012/161-32. All patients were invited to contact the first author or their healthcare professional at the clinic if they felt distressed after the interview.

Results

Self-care was identified as consisting of these four categories: symptom recognition, handling symptoms, planning life, and seeking new options. Ten subcategories emerged from the analysis of the interviews as well (Table 3).

Symptom Recognition

Symptom recognition varied on the basis of both medical treatment and IBD symptoms. Symptom recognition was described in two subcategories of physical sensations and psychological sensations.

Physical Sensations

The informants described various types of symptoms from the gastrointestinal tract such as diarrhea and bloody stools as well as constipation, swollen stomach, abdominal gas, satiety, and pain. Pain in the gastrointestinal tract was experienced as constant or nagging and intermittent as precipitated by events such as toileting. The pain was described as a knot in the intestines and associated with both loose and hard stools.

TABLE 2. Example of the Analysis

| Meaning Unit (Words and Phrases) | Code | Subcategory | Category |
|--|-------------------------------|--------------------------------|---------------|
| If I know I'm going to some sort of event and there's no access to toilets, I always try to think about that, that I need to plan a bit. | Planning of access to toilets | Planning when to do activities | Planning life |

Before then it was so loose, I don't know how to put it, because it feels like an explosion in your stomach, and at the same time there's no way you could stop it but it happens where you're standing. (Informant 13)

Participants were aware of symptoms such as joint pain, nausea, vomiting, and heartburn. Joint pain occurred because of side effects from medicines. Nausea, vomiting, and heartburn were described in relation to meals, travelling, and periods of constipation. Tiredness was described as a lack of energy due to medical treatment and joint pain that induced tiredness. Patients expressed difficulty falling asleep and having a hard time getting up in the mornings.

And then I suppose it's the tiredness, I mean you don't have the energy... and you run out of steam and when you have gone all out and become tired it takes longer to recover than before.... (Informant 19)

Psychological Sensations

Various types of psychological sensations were expressed as a response to the stress of having IBD. Stressful situations were meal times, work situations, and periods when many activities were scheduled. In work situations, informants expressed stress related to shift work and stress regarding the need to be punctual. It was also difficult to squeeze lot of activities into the work schedule.

I worked in two shifts and started working daytime, and then I felt worse. I suppose that's what triggered it. I suppose it has to do with regular habits, and time-keeping stresses me out a bit.... (Informant 12)

Loneliness, aggressiveness, and symptoms of depression were also expressed. Loneliness was described as being unable to share their feelings about IBD with anyone else or let anyone else into the world of their disease.

It's quite lonely and it's hard to find new friends, what I've got left are my friends from x, I have no new friends here, none actually.... (Informant 5)

Handling of Symptoms

An element of self-care is the handling of symptoms and this category emerged with four subcategories:

adapting the diet, using medical treatment, stress managements, and using complementary alternative medicine (CAM).

Adapting the Diet

The informants varied widely in their dietary descriptions. Much thought was given to decisions about what to eat and when to eat. The informants tried to think of what to eat and what occasions to eat. Adapting the diet concerned primarily the portion size. However, there were also situations when they avoided eating anything to prevent bowel symptoms.

Avoid eating portions that are too large.... (Informant 5)

Informants expressed the need to have time to eat if they were to control symptoms. Some described how eating regular meals was necessary and that skipping meals made them feel ill. Other informants expressed avoiding an empty stomach and the need to eat foods that calm the stomach.

Some informants were willing to try anything that may possibly alleviate their symptoms. Adapting the diet was done by trying to eat a more healthy diet with fresh fruit, vegetables, whole grain products, and fresh food as well as to emphasize cooked food, homemade cooking, low-fat foods, foods advertised as gentle for the gastrointestinal tract, and the use of probiotics. Furthermore, they tried to make sure that foods were full of nutrients and vitamins, so they often augmented

TABLE 3. Description of Subcategories and Categories

| Subcategories | Categories |
|---|---------------------|
| Physical sensations Psychological sensations | Symptom recognition |
| Adapting the diet Using medical treatment Stress management Using complementary alternative medicine | Handling symptoms |
| Planning when to do activities Planning when to refrain from activities | Planning life |
| Seeking information Personal contacts | Seeking new options |

these with multivitamins and magnesium. Others expressed the need for balance in life and reported eating all kinds of food, and eating and drinking as usual. Others expressed the desire to eat regular potluck, noting that eating a balanced diet and limiting dietary content to avoid bowel symptoms was difficult. However, some expressed that although they think about what they eat, they live a normal life and experience few, if any, obstacles due to the disease. Some informants expressed how they eat very spicy foods and never have any problems. Others expressed a love of spicy food but they now eat less of it because of their bowel problems. Diets with spices such as ginger, turmeric, cinnamon, and coriander were described as helpful by some.

Fresh food is good for me, not tinned food. (Informant 4)

Self-care also was described as trying to limit intake of food such as gluten, fatty foods, dairy products, eggs, fiber, junk food, and spicy food. For some this involved excluding coffee and tea and limiting sugar products and potato chips. Some informants also tried to avoid meat and fried foods. Others noted that fruits like apples and oranges, and vegetables like onions, turnips, and cabbage caused symptoms. In adapting the diet, some had followed advice from healthcare professionals regarding excluding milk products. The informants reported feeling better after making adjustments to the diet, but when they were careless, symptoms like a stretched and swollen belly returned.

I don't eat fatty food. If I was to eat portions that are too large it would kick off big time. I have to be careful, I can't scoff a bag of crisps or a pizza, it spoils too much, it's not worth it. (Informant 19)

Alcohol caused symptoms for some, regardless of the amount. Other informants described drinking alcohol at dinner without any symptoms.

Using Medical Treatment

Using medical treatments for prevention and maintenance was a commonly described element of self-care. Some expressed how the disease takes care of itself and that they only take their medicines without needing to modify their lifestyle otherwise. Confidence with immunomodulator medication was described, but rectal medication and cortisone were described as tough medical treatments. The informants described taking the medicines that their physician decided on and how they follow the medical treatment plan.

There is nothing I can do myself with medication ... it has been tested out for me.... (Informant 3)

Stress Management

Regular physical activity was one way these informants decreased their stress. The informants emphasized the importance of exercising, and physical activity was considered to be a cornerstone of feeling good. Activities these participants engaged in included biking, walking, running, use of the tread mill, and more intensive training like hockey, skiing, and gym workouts. Pedometers were used by some to track daily walking. Some informants also described the negative aspects of physical activity.

I used to be the type of person who would go running three times a week and be active in clubs and work a lot. I used to think that I would take some time off and rest, and then start exercising again, but that type of self-care wasn't good at all because the energy I had was used up when I tried to run and then I was sick for weeks. (Informant 16)

Sleep was described as a way to manage stress. Resting during the day and using a routine to manage daily life with regular sleeping habits were described as a way to deal with stress. Finding joy in life was expressed as important. Sadness came intermittently and informants described that it was necessary to find out what you were interested in, such as listening to books, listening to music, or playing an instrument.

Using CAM

Self-care of symptoms also consisted of using CAM. At relapse, informants used heating pads to relieve the pain, enabling them to fall asleep. Others reported trying different options such as daily intake of alcohol with spices to relieve symptoms.

My stomach has been causing me problems for many years ... and I tried all sorts of household remedies. (Informant 13)

Planning Life

Self-care was also described as planning life, with two subcategories: planning when to do activities and when to refrain from activities. Some informants had lived with the disease for a long time and described a normal life without any differences in their situation compared with family members. Other informants mentioned that they were trying to live in a special way to take care of their bodies so they would feel as good as possible.

Planning When to Do Activities

Planning activities was based on access to toilets in the environment and the need to ensure that a toilet was

available when needed. The informants expressed the need to run to the toilet all the time and that there was nothing else to focus on. Some periods were worse; after eating, they needed a toilet directly. The need to plan activities to avoid symptoms was described in relation to meals, work, shopping, and travelling.

... think about when you want to go somewhere far... I can't eat and drink before so that you are one step ahead. (Informant 14).

Planning When to Refrain From Activities

Symptoms caused informants to refrain from social activities such as hobbies. Worries and concerns were expressed because of the risk of abdominal symptoms. Difficulties finding a toilet and access to appropriate food when travelling were described as both degrading and tedious. In critical situations with frequent diarrhea, the informants exercised but had to go to the toilet all the time. Some informants stopped exercising because of symptoms and refrained from engaging in hobbies or overnight stays.

Seeking New Options

Informants described trying to be open-minded and seeking new options. If the symptoms did not disappear, they considered other options. These options centered on seeking information and making personal contacts with individuals who could help them.

Seeking Information

The informants described needing information about the consequences of specific foods and obtained such information from the Internet, reading, and lectures.

... I'm open to trying new things. If something turns up that they think is good, I'm always willing to try... (Informant 19).

Personal Contacts

Personal contacts with friends and healthcare providers were used to facilitate self-care. Personal contacts provided advice and support. Healthcare providers were accessed for emergency appointments in addition to regular check-ups. The informants felt comfortable calling the clinic when they simply could not deal with life because of intractable symptoms. They described a good relationship with healthcare professionals, especially the nurses who were easy to contact by phone or Internet.

The Department of Gastroenterology is a great support. You only phone up and record a message if you have

questions or problems, or whatever. It works really well I think, and I have a really good doctor that I have confidence in. (Informant 6)

Discussion

To our knowledge, this is the first study with a qualitative inductive design that explores self-care from a new perspective through interviewing patients with IBD about their self-care. The main significant findings for self-care were in the four categories of symptom recognition, handling of symptoms, planning life, and seeking new options.

Symptoms were described as both psychological and physiological sensations that were often debilitating and in line with our previous results (Lesnovska et al., 2013). These findings are consistent with those of others who described how symptom control can be problematic for individuals with IBD (Farrell & Savage, 2012). One reason why the symptoms are so debilitating is that the symptoms of IBD are so diverse. Simply, the variety of possible symptoms impairs symptom recognition and treatment with individual variations.

One major finding was that patients with IBD handle their symptoms by adapting their diet, but this approach is particularly difficult because the evidence of what foods are good for patients with IBD is unclear. Because of this lack of clarity, IBD patients and especially patients with CD often experience malnutrition (Skrautvol & Nâden, 2011). Dietary studies for patients with IBD distinguish between essential energy intake, dietary risk factors, and therapeutic benefit of dietary interventions (Yamamoto, 2013). There is insufficient evidence to guide advice on enteral nutrition to maintain a remission (O'Connor et al., 2013). Research is needed to develop strong scientific evidence that can guide healthcare professionals giving dietary advice.

Patients in this study described taking their medicines and follow the medical treatment plan. According to consensus reports, medical treatment for patients with CD and UC involve primarily medications to induce and maintain remission (Dignass et al., 2010; O'Connor et al., 2013; Van Assche et al., 2013).

Previous studies in patients with IBD have shown that physical activity has a positive influence on psychological well-being and quality of life (Packer, Hoffman-Goetz, & Ward, 2010; Van Assche et al., 2013). Physical activity also may be beneficial in reducing the symptoms of IBD, and low-intensity training does not exacerbate the condition and may provide a psychological benefit (Bilski, Mazur-Bialy, Wierdak, & Brzozowski, 2013; Ng et al., 2013). Evaluation of the duration and intensity of exercise programs is necessary to find a level of activity that is good for an

individual patient (Bilski et al., 2013). Stress management does not appear to improve disease course or reduce relapse in patients with IBD but might improve quality of life, particularly in patients with UC (Boye et al., 2011). Sleep disturbances might affect quality of life and gastrointestinal symptoms (Ranjbaran, Keefer, Stepanski, Farhadi, & Keshavarzian, 2007). This is why regular sleep hygiene self-care activities as recommended to patients with sleep disturbances may support better sleep (Yngman-Uhlin, Fernström, Börjeson, & Edéll-Gustafsson, 2012).

A prerequisite for a good quality of life among the informants was planning life and seeking new options. Kane, Loftus, Dubinsky, and Sederman, (2008) declare that many patients do not have sufficient knowledge to be able to manage symptoms, which in turn can lead to relapse and increased morbidity. Knowledge about the disease affects self-care and among patients with IBD, there is poor congruence between disease knowledge and symptoms (Kane et al., 2008). Previous studies show that patients want to know more about symptoms, the cause of the disease, diet, and prognosis (Barlow et al., 2010; Biancone et al., 2008; Pihl-Lesnvska et al., 2010).

Methodological Issues

Qualitative interviews were appropriate to explore self-care among patients with IBD because so little is currently known about self-care in these patients. Qualitative content analysis allows the researcher to assess the variations that occur in the text (Hsieh & Shannon, 2005; Polit & Beck, 2012). Credibility has been achieved through engaging the authors in reading the interviews and analyzing the data. Collaboration among the coauthors ensured the credibility of the codes, subcategories, and categories. Quotations have been used to increase the credibility of the categories. To address confirmability, explanations are provided regarding how interpretations were performed, aiming to facilitate and clarify this process for the reader (Tables 2 and 3). Furthermore, truly following and giving a clear description of the method enhance the dependability of the findings. One weakness might have been not using member checking; but to strengthen transferability, the context is described, a description of the informants is provided, and the analysis process is explained in detail (Lincoln & Guba, 1985).

Relevance to Clinical Practice

A decision to actively participate in the care of a chronic illness is a prerequisite for self-care. Healthcare professionals must consider patients' potential for and desire for self-care when giving advice on self-care activities. Doing so may be effective in a healthier life.

Conclusion

Self-care consists of symptom recognition, handling life through planning, and accommodating to the existing situation with the ultimate goal of maintaining well-being. Being one step ahead facilitates life with IBD. ✪

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