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ORIGINAL ARTICLE

What do patients need to know? Living with inflammatory bowel disease

Katarina P Lesnovska, Sussanne Börjeson, Henrik Hjortswang and Gunilla H Frisman

Aims and objectives. To explore the need for knowledge as expressed by patients diagnosed with inflammatory bowel disease.

Background. Inflammatory bowel disease has a major impact on physical and emotional well-being, placing considerable demands on patients' management of daily activities. Although inflammatory bowel disease patients' level of knowledge about their disease has been previously studied, it is necessary to learn more about their self-expressed needs.

Design. The study was designed to explore patients' need for knowledge; therefore, an inductive method was chosen.

Methods. Thirty patients with inflammatory bowel disease were interviewed. Content analysis was used to describe their need for knowledge.

Results. The analysis generated three categories and eight subcategories: (1) knowledge related to the course of the disease (subcategories: understanding causal relationships between symptoms and the disease, complications related to the disease and understanding treatment), (2) knowledge related to managing everyday life (subcategories: behaviour that enhances well-being and managing social life) and (3) difficulty understanding and assimilating information (subcategories: shifting knowledge needs, help to understand information and reasons for wanting or not wanting knowledge).

Conclusion. Knowledge needs were related to what to expect when living with inflammatory bowel disease in order to manage everyday life. There was a great variation in the need for knowledge, which was greatest immediately following diagnosis and during relapse.

Relevance to clinical practice. It is important for healthcare providers to ascertain the patients' individual knowledge needs and together with them formulate an individual care plan that gives the patient the necessary knowledge to manage their health and social life.

Key words: content analysis, Crohn's disease, knowledge need and ulcerative colitis

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Introduction

Inflammatory bowel disease (IBD) mainly comprises ulcerative colitis and Crohn's disease. IBD often has an early onset in life and is of a chronic or relapsing nature, frequently requiring surgery and/or lifelong maintenance drug

treatment (Loftus *et al.* 2002). Living with IBD can have a major impact on the patients' physical and emotional well-being, placing considerable demands on their management of daily activities such as social function/interaction, family life, and work or studies (Stjernman *et al.* 2008, 2010, Lesnovska *et al.* 2010).

Authors: Katarina P Lesnovska, RN, MsN, PhD Student, Department of Medical and Health Sciences, Linköping University and Department of Gastroenterology and Hepatology, University Hospital of Linköping, County Council of Östergötland, Linköping; Sussanne Börjeson, PhD, RN, Associate Professor, Department of Medical and Health Sciences, Linköping University, Linköping; Henrik Hjortswang, MD, PhD, Associate Professor, Division of Gastroenterology and Hepatology, Department of Clinical and Experimental Medicine, Linköping University and Department of Gastroenterology and Hepatology, University Hospital of Linköping,

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

Correspondence: Katarina P Lesnovska, PhD Student, Department of Gastroenterology, Linköping University Hospital, 581 85 Linköping, Sweden. Telephone: +46 10 103 8133.

E-mail: katarina.pihl.lesnovska@lio.se

Information is essential for helping the patient to manage and accept the disease. It has been found that the more the patients know about their disease, the more compliant and satisfied with their treatment they are likely to be (Robinson *et al.* 2001).

It is essential to reflect on how to communicate the information to the patient, which requires an understanding of how each individual acquires knowledge. Knowledge acquisition is a complex cognitive process of perception, learning, communication, association and reasoning, closely linked to health behaviour (Gochman 1997).

The terms knowledge and information are often used more or less interchangeably, although there are important differences. In this study, knowledge is defined as information that is given meaning through interpretation and specific to a particular context, thus dependent on the time and place where it is received (Liebowitz 1999).

There is a wide variation in the level of knowledge reported by patients (O’Sullivan & O’Morain 2000, Leong *et al.* 2004, Rezailashkajani *et al.* 2006) although previous studies indicate that they want knowledge about IBD and wish to meet other patients in the same situation (Larsson *et al.* 2003, Oxelmark *et al.* 2007). The importance of patient education and increasing their level of knowledge has become more widely acknowledged in IBD management. It is essential to be aware that making information available to the patient and offering education is not the same as asking about their specific knowledge needs (Thompson 2000). To increase patients’ knowledge of their disease, group-based intervention programmes have been tested, and those with health-related quality of life as a primary objective evaluated (Larsson *et al.* 2003, Oxelmark *et al.* 2007). The educational interventions were appreciated by patients but did not lead to increased health-related quality of life.

The heterogeneity of knowledge needs in a group of patients who all have the same diagnosis places considerable demands on healthcare professionals because the information must be individualised to support each patient in the best possible manner (Raynor *et al.* 2007).

Therefore, one must ask: What are the goals of patient education, how can such education be best provided and what should an educational programme contain?

Studies have started to identify some knowledge areas of importance to patients with IBD (Scholmerich *et al.* 1987, Eaden *et al.* 1999). In a previous study of what patients know about their disease, Eaden and co-workers developed a 24-item questionnaire, the Crohn’s and Colitis Knowledge Score (CCKNOW), containing questions about the patients’ knowledge of the disease and its course, medication and nutrition (Eaden *et al.* 1999). As a complement to these

predefined questionnaires, an approach is necessary where patient freely have the opportunity to describe their knowledge needs. A qualitative study was chosen to obtain deeper insight into patients’ knowledge needs in relation to IBD.

The aim of this study was to explore the need for knowledge as expressed by patients diagnosed with IBD.

Materials and methods

Methods

The method chosen was inductive qualitative interviews. Content analysis was employed to explore the knowledge needs of patients suffering from IBD (Krippendorff 2004).

Participants and procedure

The participants ($n = 30$) were selected from an outpatient clinic in south-eastern Sweden, and their background data are presented in Table 1. The selection was made in such a way as to ensure maximum variation in age, sex, diagnosis, duration of IBD and history of previous surgery. Patients who agreed to participate signed an informed consent form and returned it in a prepaid envelope. Two pilot interviews were conducted to test the interview questions. The first author conducted all interviews, 27 in a room at the hospital and three in the patients’ homes in accordance with the patients’ wishes. The interviews lasted for a mean of 40 minutes (range: 14–67 minutes) and started with one open-ended question: Could you please describe your knowledge needs related to living with IBD? Probing questions were posed to encourage the patients to elaborate on and explain their need for knowledge in order to access

Table 1 Background data of the participants

Variable	$n = 30$ (%)
Age (years)	29–83
Gender	
Male	14 (47)
Female	16 (53)
Type of IBD	
Crohn’s disease	18 (60)
Ulcerative colitis	12 (40)
Duration of IBD	
0–5 years since diagnosis	8 (27)
>5–10 years since diagnosis	4 (13)
>10–15 years since diagnosis	6 (20)
>15 years or more since diagnosis	12 (40)
Medical maintenance treatment	29 (97)
Surgical procedures	11 (37)
Stoma patients	1 (3)

IBD, inflammatory bowel disease.

deeper aspects of the phenomenon. Demographic data were collected at the end of each interview. Three patients (10%) were born outside Sweden, which is just below the percentage (15%) of immigrants in the total population. Five were on sick leave, three were unemployed, five had a retirement pension and 17 were employed or studying. Five had a third-level education. At the time of the interview, four were in relapse and the rest in remission.

Analysis

Qualitative inductive content analysis was used (Krippendorff 2004). Interviews were digitally recorded and transcribed verbatim by the first author. The transcribed interviews were read to obtain an impression of the text as a whole. Sentences or phrases containing information relevant to the aim and the research question were identified and constituted meaning units. The surrounding text was kept to preserve the context. The meaning units were thereafter condensed to reduce them but still retain their essence, after which they were compared to find similarities and differences. Similar meaning units were given the same code. The codes were then categorised into subcategories and categories, each describing a specific type of knowledge need. In this process, the research group worked individually in order not to interfere with their fellow researchers' assessment and analysis of the transcribed text. The analyses were then compared and consensus reached. The meaning units and subcategories were subsequently reread to determine the category for each meaning unit and subcategory (Krippendorff 2004).

Ethical considerations

The Regional Ethics Committee approved the study. In accordance with the Helsinki Declaration, the patients were assured of confidentiality and the voluntary nature of participation throughout the process.

Results

The qualitative content analysis generated three categories and eight subcategories (Table 2). The three categories

were: (1) knowledge related to the course of the disease, (2) knowledge related to managing everyday life and (3) difficulty understanding and assimilating information.

Knowledge related to the course of the disease

Understanding causal relationships between symptoms and the disease

The patients' knowledge needs focused on IBD symptoms and the course of the disease. They wanted to know how many times relapse could occur, whether every patient who has had the disease for a long time requires surgery and whether they could become experts on their own disease by gaining knowledge about each of these issues:

How many times can you have this kind of inflammation and how long will it take before some kind of operation becomes necessary? These are things I think about a lot. (no. 11)

Patients frequently remarked that they needed more knowledge about anatomy, the body's normal functions and the cause of the disease. They wanted to know, for example, whether joint pain, fever and fatigue were associated with the disease as well as whether some symptoms reinforced each other. Patients who did not want to know the causes of the disease explained that such knowledge merely created a feeling of guilt or that more knowledge seemed pointless as there was no cure.

Some were of the opinion that it was sufficient if the physician had knowledge of the disease; what was important for the patients was having enough knowledge to know when the symptoms indicated that they should contact a healthcare professional.

Complications related to the disease

Some patients found it reassuring to learn about the risks and complications that could occur, while others deemed it pointless. Those who did not want such information argued that it only created anxiety about something that might never happen. Patients who wanted to know about possible complications considered such knowledge valuable because

Table 2 Categories and subcategories

Knowledge related to the course of the disease	Knowledge related to managing everyday life	Difficulty understanding and assimilating information
Understanding causal relations between symptoms and the disease	Behaviour that enhances well-being	Shifting knowledge needs
Complications related to the disease	Managing social life	Help to understand information
Understanding treatment		Reasons for wanting or not wanting knowledge

it would help them to be vigilant, be on the alert for symptoms and seek preventive or maintenance treatment in good time:

When I find out what can happen I do not become afraid, it's really important for me to know what can happen. That I receive clear answers and not information that paints a more rosy picture. (no. 14)

Understanding treatment

Patients wanted to receive objective drug-related information from the healthcare professionals:

It's only in the past few years that they have asked how I am feeling and if I have taken my medication and ... for many years I did not take any medication.... but nobody actually asked me if I was taking it... no... Now I understand that it's necessary and beneficial because ... you can avoid a relapse... (no. 13)

Information about medication helped patients to become more vigilant about possible serious symptoms and prepared them to make decisions about ceasing or changing treatment. When the healthcare professionals failed to ask whether or not they took their medication, the patients believed that close adherence to the medication regimen was not important.

Knowledge related to managing everyday life

Behaviour that enhances well-being

The patients required knowledge about how to behave in everyday life in order not to cause deterioration in their condition. Knowledge about what to do to prevent relapse and remain in remission helped them to feel that they could manage everyday life to a greater extent than before. Diet was another subject that they wanted to learn about, as it was something they could influence themselves. Experience had taught them what they could and should not eat. The information received from healthcare providers about diet was limited. They stated that diet is an area of importance because it concerns not only eating but taking part in social events, about which they had mixed feelings. Patients wondered if following the wrong kind of diet could trigger a relapse or worse symptoms. Their experiences were highly individual:

Information about something I can manage myself is extremely important, for example, if intake of alcohol and dairy products is not good... (no. 7)

Knowledge of what might control or aggravate the disease was important. If the patients knew what aggravated

the disease, it would make it possible to avoid these situations and prevent the symptoms. They wanted to know more about how to handle a relapse, when to contact a healthcare provider and what they could do to avoid hospitalisation.

Managing social life

Managing social life requires communicating knowledge about the disease to significant others. Some considered it important that family, friends and colleagues had knowledge about the disease. Several patients felt that their next of kin had a greater need for knowledge than they themselves did, while others were of the opinion that it was shameful to talk about intestinal symptoms:

My wife's extremely worried, so she tries to obtain as much knowledge as possible. (no. 8)

Managing social life was also associated with being questioned and criticised by colleagues. Deciding whether or not to tell others about the disease and its symptoms was experienced as a dilemma.

Difficulty understanding and assimilating information

Shifting knowledge needs

There was a greater need for knowledge in connection with diagnosis, during relapse and when the patients had lived with the disease for a long time and realised that they had received insufficient information at diagnosis. They would have preferred a long conversation with their physician on the occasion of the first diagnosis. It was sometimes difficult to assess the importance of the information they received as a newly diagnosed patient. Because of the relatively large amount of information provided at the time of diagnosis, some felt that the disease sapped all their energy and occupied their thoughts. Two patients were first diagnosed as suffering from ulcerative colitis, and Crohn's disease was only diagnosed at a later stage but without any explanation of what the new diagnosis meant or the difference between them:

Yes, when I first got the diagnosis, the need for knowledge was probably more important and greater... but when I read about others, it feels as if I have a less serious disease ... (no. 24)

The methods of acquiring knowledge also changed during the course of the disease process. Although some patients valued receiving information verbally, they also

wanted it in written form or to receive tips on Internet so that they could find information themselves. Teaching aids such as posters with pictures of the anatomy of the human body were appreciated. They said that information should be provided in relatively simple language that they could understand. There was also curiosity about and a need to obtain knowledge of new research findings. The patients wanted to be updated when something new happened in the field. It was reassuring to receive an update from the healthcare provider. Another way to satisfy the need for knowledge was to learn from fellow patients' experiences. Some patients appreciated being a member of the patient association, while others felt afraid to learn from other patients' experiences. They also pointed out that an economic issue could arise if they were unable to afford the patient association's membership fee. Some patients said that when hospitalised and sharing a room with one or more patients with the same condition, they appreciated sharing experiences and being supported or giving support.

Help to understand information

The patients reported that the information sent to them was not always helpful and at times difficult to understand. They also noted that they did not know how to interpret, for example, blood sample reference values. Some read about the disease on the Internet but said that they often found it difficult to interpret the information and even to know which sites were reliable. Several commented that it is better to have a discussion with a nurse or physician than be obliged to base their knowledge on the printed information sent to them. Telephone contact with a nurse was also described as valuable:

Sometimes when I've had questions I've called my nurse and received an answer. Sometimes you get worried when you receive a sheet of paper saying that the test results were a bit..., and no explanation and such things. (no. 20)

Reasons for wanting or not wanting knowledge

A number of the patients said that they only had a limited need for knowledge, but the reason differed from patient to patient. Some had a sense of security and trusted their physician and hence had no need for any additional medical information. Others did not want information because they believed that it might make them frightened:

I do not know if it would be better to know more, I would not feel any better in any case, I don't think so....anyway. (no. 27)

There were also patients who expressed a great need for knowledge, explaining that being well informed gave them a sense of security. These patients wanted to know more about their disease so that they would be able to influence their care and believed that the opportunity to be a part of the decision-making process was greater if they knew more about their illness.

Discussion

As far as we are aware, this is the first study to use a qualitative approach to explore the IBD patients' self-reported knowledge needs in depth. Previous researchers have employed questionnaires containing items based on the assumptions of healthcare personnel. The qualitative approach in the present study contributed interesting new data that complement previous research by providing a deeper insight into the individual knowledge needs of patients with IBD.

The main results are: (1) Most of the patients wanted to know more about the course of their disease. (2) They wished to receive information that enabled them to take care of themselves more actively. (3) Healthcare professionals must become aware that knowledge needs are often highly individual and can change over time.

Obviously, patients suffering from IBD require basic knowledge to enable them to manage the disease, alleviate their worries and improve their compliance. Cooper *et al.* (2010) demonstrated that being familiar with the nature of the condition is important for patients with IBD, although developing a sense of control and being able to predict outcomes can be difficult. Knowledge of the expected course of the disease while at the same time being unable to control and predict it was described as distressing by some patients, while others did not consider it a problem (Cooper *et al.* 2010). Some patients in our study did not understand the importance of adherence to medication until the physician raised the question. Casati *et al.* (2000) have demonstrated that more knowledge led to increased compliance, while Moradkhani *et al.* (2011) found no such relationship. In one quantitative study based on questionnaires, it was revealed that lack of knowledge of IBD complications can have disastrous consequences leading, for example, to an underestimation of the importance of colorectal cancer screening (Subasinghe *et al.* 2010).

Patients in this study expressed great interest in behaviour that leads to improved well-being and were positive towards the idea of making behavioural changes. They had a great need for knowledge about self-management and behavioural changes to influence their well-being and the

progression of the disease. In the context of health-related behaviour, it is assumed that individuals value the opportunity to avoid disease and believe that specific actions/behaviour may prevent or improve it. One health-related behaviour framework is the health belief model (HBM) that includes the following elements: beliefs about the likelihood of being afflicted by a disease and attitudes to the seriousness of contracting a disease or leaving it untreated (Rosenstock 1960, Rosenstock *et al.* 1988). One reason why the patients in our study were motivated to make behavioural changes might be the insight that there is a link between eating certain types of food and symptoms that reduce their well-being. Thus, their motivation became stronger when they understood the benefits of behavioural changes concerning the choice of food. Achieving better well-being as a consequence of a change that they themselves had made led to a sense of control over the disease and a feeling of empowerment. The results of our study are supported by the findings of Bernstein *et al.* (2011) that patients need information in areas of medical aspects, treatment and self-management. Our study also reveals that there is a need for knowledge in areas besides these, such as being involved in their own care as an active part in the decision-making process, having knowledge about the natural course of the disease and the great variation in the knowledge need.

There are many ways to educate patients with chronic diseases; the question is how to achieve the best results. Multiprofessional group-based educational programmes have been appreciated by patients, although extensive evaluation of the content is limited (Jaghult *et al.* 2007). These programmes are based on clinical experience and the literature (Larsson *et al.* 2003, Jaghult *et al.* 2007). Education per se does not seem to lead to better health and well-being. Thus, the patient should be informed about available self-management techniques and how they can be used to make each individual more responsible for their own care (Barlow *et al.* 2010).

Our study revealed a varying need for knowledge, where the greatest need was at the time of diagnosis, as some patients reported receiving inadequate information at that point. A great need also arose during relapse. Although many different factors probably combined to explain the reasons for wanting or not wanting knowledge, we found that some patients had no interest in receiving information, which can be considered a coping strategy to protect them (avoidance behaviour). Other patients searched for knowledge on the Internet, from the physician, the IBD nurse, the library and the patients' association and in numerous other ways. These two types of patients have been labelled 'blunter' and 'monitor' by Miller (1987). 'Monitors' are people

who seek information that can help them cope with stress, while 'blunters' avoid any new information when faced with a stressful situation (Miller 1987). Although monitors generally tend to scan for threatening information about their health, in certain situations they may wish to avoid such information. In general, monitors become more avoidant when the threat is severe, chronic or uncontrollable (Miller 1995). Using open questions and paying attention to feedback from the patient, one can identify additional needs. In a structured care plan, the patients' knowledge needs are addressed by ensuring that the information is individualised and concretised and consists of what is important for that particular patient, including guidance on how to cope with various situations when living with the disease. Many important questions remain unanswered: How is it possible to ascertain that the patient is receptive to information? How can one ensure that the patient understands the information and has sufficient knowledge? Which kind of knowledge is most important, general knowledge or knowledge that is specific to the individual? How can these be balanced? Should we just provide the information the patient requests or is there information that should be provided to all patients? Perhaps healthcare providers could list the patients' knowledge needs in collaboration with them, thus constituting individualised care.

Strengths and limitations

One strength of this study is the strict adherence to the content analysis process aimed at producing replicable and valid results (Krippendorff 2004). The patients were selected in order to obtain the greatest possible variety of aspects of IBD patients' need for knowledge, which strengthens the validity of the results. Another strength is the large number of patients ($n = 30$), as the sample size in qualitative studies is usually considerably smaller. Validity was also established by presenting relevant quotations from the transcribed text to further illustrate the categories. Seeking consensus between the co-researchers throughout the analysis process also contributed to the validity of the results. Reliability was increased by conducting two pilot interviews to ensure that the questions were relevant and properly formulated as well as by the fact that the interviews were conducted and audio-taped by the same person. All authors selected meaning units from the first three interviews, while in the following 10 interviews, the first and last authors selected meaning units individually and compared them to ensure validity and reliability. The detailed description of the participants, data collection, analysis and study context permits the reader to assess the transferability of the results (Morse *et al.* 2002, Krippendorff 2004).

One limitation is the fact that the aim of the study was to explore patients' knowledge needs. However, when the interviewer asked the informants about their need for 'knowledge', they frequently used the word 'information' and mainly referred to their need for it. There may be a risk of confusion when two such similar concepts are used on the same occasion. This fact has been taken into account in the data analysis to distinguish between the concepts as far as possible. It might have been better to have clarified the difference between knowledge and information at the start of the interviews.

In conclusion, this qualitative study adds new knowledge describing that patients' desire for knowledge about their chronic disease and its course as well as what to expect in order to better manage everyday life. They also wanted information about how to take care of themselves in the best way possible. Their knowledge need was greatest when first diagnosed, during relapse or when they had lived with the disease for a long time but had received insufficient information at diagnosis. The study also highlighted a great variation in the need for knowledge between individuals but also in the same patient over time.

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