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Reconstruction of individual, social, and professional life: Self-management experience of patients with inflammatory bowel disease

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Abstract:

BACKGROUND: Patients with inflammatory bowel disease (IBD) experience wide range of physical and psychological problems experience. The use of strategies to improve disease management by patients is of has special importance in solving these problems. The aim of present study was to discover the strategies and behaviors of patients to manage their disease.

MATERIALS AND METHODS: The present study was conducted with a qualitative research approach and a qualitative content analysis method. The research participants included 20 patients with IBD referred to gastrointestinal wards in 2020 in Mashhad. Data were collected through unstructured interviews and purposeful sampling method and continued until data saturation. Data analysis was performed continuously and simultaneously with data collection and comparatively.

RESULTS: Data analysis provided five themes of “Improving self-efficacy and problem-solving skills,” “Coexistence with disease,” “Reviewing and modifying of interactions,” “Adjusting job and professional conditions” and “Commitment to self-care.” The combination of these concepts indicated that is the main theme in disease management for these patients.

CONCLUSIONS: Reconstruction of individual, social, and professional life can improve self-regulation and problem-solving skills in these patients and make them a sense of control on their lives and disease.

Keywords:

Activities, disease management, inflammatory bowel diseases, qualitative research

Introduction

Inflammatory bowel disease (IBD) is a chronic recurrent gastrointestinal disorder that has an unpredictable course. Patients with IBD experience wide range of social, physical, and psychological problems and these factors significantly affect patients' experience and perception of their disease.^[1] The main concerns of patients with IBD were reported to be reduced quality of life, side effects of medications, unpredictability, psychological and physical complications,

the need for surgery, and the risk of cancer.^[2-5] All of these concerns are key factors and can result in a negative course of the disease and a poorer response to treatment, and finally affect the patient's management of the disease.^[6] Improvements in health care have led to more people living longer with multiple chronic illnesses. With this change, chronic illness is now the main focus of health care. At the same time, more attention has been concentrated to chronic symptom management approaches to maintain patient independence and quality of life over a longer period of time.^[7,8] Disease

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management process in chronic diseases is a dynamic and ongoing process, during which patients identify their needs through multiple strategies and combine them to cope with the disease during daily life. These strategies are multidimensional, since they combine individual need with intrapersonal, interpersonal, and environmental systems to maximize the level of health.^[9] In the nursing and medical literature, the concept of management of disease-related behaviors can be described as measures that people with chronic disease take with regard to their disease management in various dimensions such as medical management, role management, and emotional management. Medical management may include attending regular doctor's appointments, medication therapy, nutritional therapy, managing symptoms such as diarrhea, pain, and fatigue, and the early detection of symptoms that can lead to a flare-up. Role management may involve managing occupational and social relationships. Emotional management may include adjusting with stress arising from having IBD.^[10] Several studies have been conducted to identify disease-related behaviors used by patients suffering chronic diseases. For example, Corbin and Strauss found that management-related behaviors in chronic patients are divided into three areas: medical management, adopting new behaviors or roles in life, and dealing with related emotions. Individual characteristics such as knowledge, self-efficacy, and self-care ability seem to influence behaviors related to chronic disease management.^[9] Successful management of disease by patients allows them to play a role as an individual in their daily lives, in the interpersonal and family environment, and as a participant in the health-care environment and in the society and also apply strategies to maximize their level of health with regard to chronic disease. It also increases self-regulation and problem-solving skills in IBD patients and allows them to feel having a control on their lives and diseases.^[11] Hence, the present qualitative research was conducted with the aim of discovering the strategies and behaviors that participants stated in response to the problems caused by this chronic disease and improving the quality of their disease management.

Materials and Methods

Study design and setting

The present study was conducted to discover the strategies and behaviors used by IBD patients to improve manage their disease. To achieve this goal, conventional content analysis method was used. Qualitative content analysis as a research method is used to interpret the content of textual data subjectively, in which explicit and implicit themes in text are identified through systematic classification process. The goal of conventional content analysis is to describe the phenomenon and

express patients' emotional reactions.^[12] The research environment in the present study was gastrointestinal wards and specialized clinics of gastrointestinal patients of Ghaem and Imam Reza hospitals in Mashhad in 2020.

Study participants and sampling

Criteria for selecting participants included having IBD, being at least 18 years old, elapsing at least 1 year after diagnosis, willingness to cooperate and participate in interviews, and the ability to provide experiences. The analysis of data of each interview was a guide for the next interview and thus sampling continued until data saturation. A total of 20 participants were interviewed.

Data collection tool and technique

The main method to collect the data was semi-structured in-depth interviews. The mean the interviews were 45 min and before the start of the interview, the aim of study and the confidentiality of information and recording of interviews were explained to participants. Then, if a participant was willing to participate in the study, interview started first with some open-ended and general questions, including "Please explain your experience of living with this disease, what problems do you face during management of your disease? What are the challenges to cope with these problems? What strategies do you use to deal with these problems?" Then, based on the answers and data provided by the participant, clarifying and in-depth questions, including such as "Explain more to me in this regard, what does this means? Please explain more" will be asked. All interviews were performed by the main researcher of study and simultaneously recorded and then typed word for word.

Data analysis was performed in line with the aim of study and based on the explanations of the research participants in this order: Data preparation, determination of semantic units, text coding, reviewing of codes with text, classification, and development of categories based on similarity and appropriateness, reviewing the categories and re-comparing with the data to ensure the strength of the codes, identifying the themes with careful and in-depth reflection, and comparing the categories with each other and reporting the findings.^[12] Lincoln and Guba criteria including credibility, dependability, confirmability and transferability were used to ensure the accuracy and reliability of qualitative data.^[13] Long-term engagement, integration in data collection, observer review, and continuous data comparison were used for credibility of data. Dependency represents the stability and reliability of data. For this purpose, member check was used in the form of using supplementary comments of coworkers and review of manuscripts by participants. Confirmability of the findings was determined by presenting reports, manuscripts and notes to two nursing

professors and obtaining a single result. Transferability of the research was obtained by a rich description of the data and selection of participants with different demographic characteristics [Table 1].

Ethical consideration

The research ethics permission was obtained from the Ethics Committee of Mashhad University of Medical Sciences under the code of IR.MUMS.REC.1396.367.

Results

The present study was a qualitative study conducted with a content analysis approach. Data analysis revealed five themes of “Improving self-efficacy and problem-solving skills,” “Coexistence with disease,” “Reviewing and modifying of interactions,” “Adjusting job and professional conditions,” and “Commitment to self-care.” The combination of these concepts indicated that patients use “reconstruction of individual, social and professional life” as their main strategy for better disease management [Table 2]. Then, each of the themes is explained along with the relevant subcategories.

Improving self-efficacy and problem-solving skills

One of the strategies used by patients with IBD to reduce pain caused by recurrence and progression of disease and better management is to improve self-efficacy and problem-solving skills by using “Development of individual knowledge about the disease,” “setting goals for recovery” and “promoting self-esteem.”

Development of individual knowledge about disease

One of the strategies used by patients in response to problems is to develop individual knowledge about the disease by searching for relevant sources and applying the results of valid studies in disease management, obtaining information from experts, using peer experiences, gaining specialized training, disease recognition and management based on experience and trial and error and learning cognitive behavioral therapy. In this regard, one of the participants stated:

“... My husband and I are constantly searching for a new treatment for this disease and its complications and we are constantly researching what is good and what is bad, and we try to observe everything that is good” (Female patient 11).

Obtaining information from experts and using the experiences of peers was another way to develop individual knowledge in patients. In this regard, one of the participants stated:

“... Since my sister had already experienced this disease and her disease had been cured, she had a lot of information, she helped me a lot. Some other physicians had sites and they had written educational articles about this disease that I read and I used them” (female patient 8).

Recognition and management of the disease based on experience and trial and error was another strategy used by some patients. In this regard, one of the participants stated:

Table 1: Demographic characteristics of the participants

Participant number	Gender	Age	Diagnosis CD UC	Disease history (years)	Occupation	Education	Marital status
Participant 1	Male	36	UC	14	Employed	Academic	Married
Participant 2	Male	27	CD	7	Employed	Academic	Married
Participant 3	Male	30	UC	3	Employed	Academic	Single
Participant 4	Male	39	CD	7	Employed	Diploma	Married
Participant 5	Female	30	UC	5	Employed	Diploma	Married
Participant 6	Male	45	UC	15	Employed	Academic	Married
Participant 7	Male	22	CD	4	Unemployed	Academic	Single
Participant 8	Female	65	UC	15	Retired	Academic	Married
Participant 9	Male	42	UC	18	Employed	Academic	Married
Participant 10	Female	32	CD	17	Unemployed	Academic	Married
Participant 11	Female	30	CD	6	Unemployed	Secondary	Married
Participant 12	Female	28	UC	4	Employed	Academic	Married
Participant 13	Female	34	UC	5	Employed	Academic	Single
Participant 14	Female	47	CD	14	Retired	Academic	Married
Participant 15	Female	26	UC	6	Unemployed	Diploma	Single
Participant 16	Female	42	UC	4	Unemployed	Diploma	Married
Participant 17	Male	29	CD	12	Unemployed	Secondary	Single
Participant 18	Female	36	UC	13	Employed	Diploma	Married
Participant 19	Male	48	CD	10	Employed	Academic	Married
Participant 20	Female	55	UC	8	Retired	Academic	Married

CD=Crohn's disease, UC=Ulcerative colitis

Table 2: Strategies used by inflammatory bowel patients in disease management process

Sub-categories	Main categories	Theme
Development of individual knowledge about the disease	Improving self-efficacy and problem solving skills	Reconstruction of individual, social and professional life
Setting goal for recovery		
Promoting self-esteem		
Understanding and accepting the disease	Coexistence with disease	
Disease adaptation	Reviewing and modifying interactions	
Effective maintenance of social interactions		
Dealing with the wrong behaviors of people around patient		
Effective interaction between patient and people around him or her	Adjusting job and professional conditions	
Quitting job		
Job change		
Job modification	Commitment to self-care	
Effective stress management		
Exercise therapy for better disease management		
Mastering the selection and implementation of proper nutrition		
Adherence to treatment		

“... If you receive a good feedback from a work you has done, you will generalize it and do it other places and if you receive bad feedback, you do not do it anymore and try to look for the next solution” (Male patient 1).

Another participant stated: “... I obtained all of them through trial and error and after making so many mistakes and errors; I could have plans for myself and select the right path” (Male patient 3).

Setting goal for recovery

One of the strategies used by patients in responding to problems was to set goals for recovery by strengthening the will to cope with disease, to seek recovery, and to make the right decision to control the disease. In this regard, one of the participants stated: “... despite all these problems, we are moving forward as much as we can so that the disease does not get worse” (Female patient 5).

Another participant stated: “... I do my best to achieve what I want and cope with my disease” (female patient 12).

Strengthening the will to cope with disease was one of the most important strategies mentioned by patients for successful disease management. One of the participants stated: “... I was thinking for hours and concluded that I should cope with my disease. I should make my best so that it does not destroy me” (male patient 9).

Another participant also stated: “... I decided to get well and I believed there was a force that would help me in this decision and it was very effective” (Male patient 4).

Promoting self-esteem

One of the strategies used by patients in response to the problems created during this disease management was to promote self-esteem by inducing a sense of vitality and youth, valuing and paying attention to your own

needs and relying on your ability to care. In this regard, one of the participants stated:

“... I feel that I have to do something for myself and be kinder to myself. I pay more attention to my own wants and I started this attention from my initial wants and desires. For example, I saw I am at work and the time has elapsed and still I has not eaten my lunch, while order in eating healthy food is one of the important issues, and that I always tried to dedicate some time to myself and achieve my desires, sit and read books, and also dedicate some time for my family and this way of thinking has had a great impact on me” (Female patient 16). Another participant also stated: “... I try to pay more attention to my appearance and beauty so that I feel young and do not let the disease annoys me” (Female patient 14).

Coexistence with disease

Coexistence with the disease was one of the strategies used by patients with IBD to better manage the disease through “understanding and accepting the disease” and “adapting to the disease.” Patients concluded that instead of challenging and passively dealing with disease, they should accept the new conditions and life with the disease and seek maximum adaptation with it to minimize their problems and manage the disease successfully. In this regard, one of the participants stated:

“... In order to be able to focus your mind on controlling and managing your disease, you should first accept the reality of your disease and your new conditions and accept living with” (Male patient 4).

Another participant stated: “... I concluded that I should look at it as a normal event, like all other events in life, and not challenge it too much” (Female patient 10).

Considering the importance of adapting to disease, one of the participants stated: “... Over time and with the effect of drugs, you understand that you should not deal with

this issue too hard and you should be able to cope with your situation and adapt yourself with it to have a comfortable life” (Male patient 1).

Review and modification of interactions

One of the strategies used by patients with IBD to better manage the disease was to review and modification of interactions through “effectively maintaining social interactions,” “encountering the misbehavior of others” and “effective interaction between patient and people around him or her.” Interviews with patients showed that one of the most important problems they face is disruption in social interactions with others, as well as encountering inappropriate feedbacks. Exacerbation of these disruptions causes many problems for patients, especially stress. One of the strategies used by many patients to solve these problems was effectively maintaining of social and family interactions. In this regard, one of the participants stated:

“... Learning to manage relationships was a very big step in controlling the condition and stress of this disease. I read many books, including communication and interaction with spouse, controlling anger and rage and I participated in several counseling sessions to learn how to change my interactions with people around myself and be more flexible” (Female patient 10).

Another participant stated: *“... My interactions are very low during the exacerbation of my disease, but I always try to keep in contact and communicate with people around me in these situations through phone calls, or in these situations, people around me try to increase their contact and communicate with me. We strongly believe in the effect of our presence and communication, and any shortcomings on my part in these interactions have been compensated by them, and this is really the need of people like us” (Male patient 6).*

Adjusting job and professional conditions

One of the strategies used by patients with IBD to reduce the stresses of life and better manage the disease was to adjust their job and professional conditions through “quitting the job,” “changing jobs” or “improving the working conditions.” Interviews with patients show that physical or psychological stress caused by professional and daily activities had a negative effect on their disease condition. Thus, to reduce these problems, patients adjust their job and professional conditions to better manage their disease. In this regard, one of the participants stated:

“... If much pressure is imposed on me while teaching, I will cancel my next class. My disease condition has caused me to reduce my workload and not accept too much class because I see that high tiredness is harmful for me” (Female patient 5).

On changing his work style to reduce the stresses affecting his disease, another participant stated: *“... After*

this disease, my job did not change, but I changed my work style and positive things happened, since when I could change my work style, physical and mental pressure on me decreased and it is harmful for my health” (Male patient 17).

Another participant also stated: *“... When my disease was getting worse and I could not attend at the company, I tried to do my works at home and it was much better for me” (Male patient 4).*

Commitment to self-care

Another strategy used by patients with IBD to better manage the disease and improve their quality of life is to commit to self-care through “effective stress management,” “exercise therapy,” “selecting the proper diet” and “adherence to treatment.” Interviews with all patients showed that life stress management, exercising, having a proper diet and fully adherence to treatments prescribed by health-care providers play a major role in the proper management of the disease and reduction of physical and mental problems caused by it. In this regard, one of the participants stated:

“... I try to work more on my mind and do more work to calm my mind and soul and take the stress away from me so that I can control my disease in this way” (male patient 9).

Considering the importance of adherence to treatment and the role of self-care in this disease, the participants stated: *“... Adherence to treatment is crucial. I try to take my drugs regularly, follow my diet, and exercise with regular walking. “I manage my stress and follow periodic visits and visits to my physician” (male patient 7).*

“... The skill of living with this disease should be learned by patients and they should learn taking care of themselves and they should know how and to modify their diet and activities and anything related to the disease” (female patient 8).

Discussion

Results of the present study included themes or concepts that showed the main strategy used by IBD patients in the disease management process and its specific features. The analysis of participants’ experiences revealed that they perceived “reconstruction of individual, social and professional life” as their main strategy in the disease management process, since after being affected by disease, patients concluded that by “improving self-efficacy and problem-solving skills,” “coexisting with disease,” “reviewing and improving interactions,” “adjusting job and professional conditions” and “commitment to self-care,” they can overcome the problems caused by this disease. Thus, “reconstruction of individual, social and professional life” was determined as the final theme and the main strategy of the patients

participated in this study. In study conducted by Zare *et al.*, the empowerment process of IBD patients in self-management were included five dimensions: self-care, psychological coping with disease, social interaction skills, disease-specific health literacy, and self-evaluation.^[14] The results of the above study are in consistent with our findings.

Sykes *et al.* noted that patients with IBD strive to control the disease, to maintain health-related normality in what they called “balancing my disease”. This struggle for normality often involved several strategies including psychological (adaptation or denial), behavioral (changing diet or seeking information), social (seeking social support), and medical strategies (taking medication).^[15] The strategies are consistent with those found in the present study. IBD patients experience many problems and worries after being affected by disease. These problems include occurrence of various physical complications, social stigma, limitations and uncertainty, disruption in quality of natural life processes, problems caused for family and friends, and many other cases that influence the patients by exacerbating and relapsing the disease.^[5,16-19] Overcoming the above-mentioned problems requires gaining the ability to properly manage the disease and having strategies appropriate to the situation, and relying on the abilities of the person. Cases such as improving self-efficacy and problem-solving ability, gaining the ability to coexist with disease and new conditions, reviewing and improving individual and social interactions that undergo many changes after disease, modifying the conditions that exacerbate disease and physical symptoms are among the job and professional conditions and most importantly, commitment and adherence to self-care and prescribed treatments. All of the above-mentioned strategies are the result of the perceived experiences of inflammatory bowel patients in their disease management process, which they have achieved it after going through difficulties and receiving various trainings. These strategies can help patients return to a normal life despite their disease. Reviewing other similar studies have indicated that IBD patients use almost similar strategies and behaviors to respond to their problems, for example, Larsson *et al.* in a review study showed that the most important strategies of participants to deal with IBD were coping and lifestyle changes through activities such as preparing for participation in social activities, positive thinking, distraction, social comparisons and acceptance of the disease.^[20] Severity of disease may alter coping strategies of patients also it appears that coping strategies may vary with relapse and remission periods. In study conducted by Plevinsky *et al.* to examine disease management strategies by inflammatory bowel patients, results showed that IBD patients’ self-management strategies are divided into three areas, including individual, patient-caregiver

communication, and social communication areas. They recommended increasing problem solving skills, self-efficacy, improving patient-care team communication and strengthening social communication to enrich the self-care of patient in each of these areas.^[11] In addition, in a study conducted by Cooper *et al.*, the main theme of “Reconciliation of the self in IBD” was mentioned as the main strategy of IBD patients in the process of disease self-management, which is in line with the themes extracted in our study. Researchers in the mentioned study reported that participants who could achieve better levels of self-control reported significantly less negative impact of IBD and felt more control on priorities of their daily life.^[21] It should be noted that there is a need to examine the phenomenon of disease management by patients as well as the help of health care providers to successfully implement strategies, adapt to themselves and unstable disease conditions throughout the course of their disease. In study conducted by Bishop *et al.*, general aspects of the management for adolescents with IBD were included a good, well-balanced diet, encouraging regular exercise, good sleep, and managing stress.^[22] The results of the above studies are in consistent with the results of our study.

Limitations

Because this study aimed to examine the experiences of disease management in relation to living with IBD, a qualitative study with open-ended questions was considered the most suitable approach. Owing to the nature of the study, the present findings are not possible to transfer to all individuals with IBD. However, steps have been taken to strengthen the credibility of the study and to support transferability of the findings to other patients with IBD. To strengthen the credibility, the purposeful sampling was intended to capture various experiences and the various genders, diagnosis and disease durations contributed to a richer variation of experiences.

Conclusions

Having effective and efficient strategies results in successful self-management, leading to increased self-regulation and problem-solving skills in IBD patients and they allow patients to have a feeling of control on their lives and diseases. Achieving successful self-management and having effective strategies require implementing interventions and care and training programs to increase health literacy, modifying behavior to improve lifestyle, developing disease-related skills and increasing patient communication with care providers. In general, by identifying the aspects of life that lead to the highest level of self-confidence in IBD patients, health care providers should design support and care programs according to their individual needs and life priorities. It

is suggested that future studies design these care and support programs.

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Conflicts of interest

There are no conflicts of interest.

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