Original Article

The components of a lifestyle based educational package for patients with ulcerative colitis: a Phenomenological Study

Mina Mazaheri[1], Asghar Aghaei[2], Ahmad Abedi[3], Hamed Daghaghzadeh[4], Peyman Adibi[5]*

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Abstract

***Background & Aims*:** Ulcerative colitis is an inflammatory chronic disease. The purpose of this study was to explore the components of the lifestyle in patients with ulcerative colitis in order to develop a particular educational package for them.

***Materials & Methods*:** The study was a phenomenological qualitative research with in-depth interviews. The participants were recruited (n=26) using purposeful sampling from the IBD outpatient clinic affiliated to Isfahan University of Medical Sciences and the private office. The sampling was done in such a way to encompass greatest variation in diagnosis and duration of UC, age, and sex.

***Results*:** A total of 26 UC patients (with mean±SD age of 39.41 ± 11.8, (57.6%) graduated from university, (84.4%) married, mean duration of disease=7.56y, and mean age of disease=31.29y) were included in the study. Using seven-step Colaizzi method, data was summarized in four main concepts and ninecomponents.

Conclusions: With the discovery of nine main components in relation to lifestyle and their impact on UC disease, a lifestyle-based educational package can be developed for UC patients. Some of the discovered components in this study did not get enough attention in the previous studies.

Keywords: Ulcerative colitis, lifestyle, qualitative researchh

***Address*:** Psychosomatic Research Center, Isfahan University of Medical Sciences, Isfahan, Iran

***Tel*:** +989133254633

***Email*:** mina.mazaheri@gmail.com

Introduction

Chronic diseases are one of the challenging situations of human life and their management is a major health problem in the communities across the world (1). Persisting for a long time, these diseases are not curable or lead to pathological changes in the individual and limit their ability in daily routine functions (2). Most chronic diseases are closely associated with lifestyle behaviors (3). The concept of lifestyle implies that people usually apply a well-known pattern of behavior in their daily lives. Now, this daily pattern of activities can be healthy or unhealthy (4). According to the World Health Organization (WHO), healthy lifestyles include behaviors that ensure the physical and mental health of humans (5). More importantly, lifestyle affects the quality of life and the prevention of diseases (6).

Inflammatory bowel disease (IBD) is a lifestyle-related chronic disease, with two main types of Crohn's disease (CD) and ulcerative colitis (UC). Although the genetic, environmental and immunological factors contribute to inflammatory bowel disease, the cause of the disease remains complex. In the past, it was thought

[1] PhD of psychology, Psychosomatic Research Center, Isfahan University of Medical Sciences, Isfahan, Iran (Corresponding Author)
[2] Professor of Department of Educational Science and Psychology, Isfahan (Khorasgan) Branch, Islamic Azad University, Isfahan, Iran
[3]Associate Professor of Psychology of Children with Special Needs, Department of Children with Special Needs, University of Isfahan, Isfahan, Iran
[4]Associated Professor of Medicine, Integrative Functional Gastrointestinal Research Center, Isfahan University of Medical Sciences, Isfahan, Iran
[5]Professor of Medicine, Gastroenterology Section, Department of Internal Medicine, Isfahan University of Medical Sciences, Isfahan, Iran

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that IBD is a Western disease, while the disease is on the increase in Asia and Latin America (7). This epidemiological change is most likely due to Westernization of lifestyle, dietary changes and health improvement as part of economic development in developing countries (8). In fact, these diseases are characterized by unpredictable relapses that occur suddenly or in response to external triggers, especially personal health behaviors (9). There is currently no definitive treatment for IBD (10).However, despite the incurable nature of the disease, a wide range of therapies, including drugs, surgery, and diet are being used (7). The goal of the treatment is to manage inflammatory bowel responses in the active period of the disease and to maintain remission with focusing on adherence to the treatment (10). Although drug therapy is the first line of treatment to improve the disease and control the physical symptoms and psychological problems in IBD patients, its related limitations have prompted the researchers to seek alternative methods for symptom management and psychological function improvement in the patients (11). Due to their nature, these diseases have a significant impact on the mental health and quality of life. Anxiety and depression are common in IBD patients that not only reduce the quality of life but also affect the clinical course of the disease (12).Therefore, psychological interventions are important in patients with IBD. Psychological interventions may manage the flare up of the disease and improve the psychological well-being and quality of life. Evidence showed that psychotherapy can have a significant impact on the psychological and clinical outcomes of the disease (13).

Promoting the level of mental and physical health in lifestyle-related diseases will require understanding about the personal characteristics and life situations that may endanger the health of the individuals. Thus, it is essential to examine the components that are considered in the lifestyle of the patients. Notwithstanding, a number of studies attempted to explicitly describe some aspects of healthy lifestyle in patients with IBD (14, 15, 16), few interventions have been conducted in this regard (17, 18). The present study seeks to explore a more effective intervention for IBD patients. Therefore, the purpose of this study was to explore the components of lifestyle in patients with ulcerative colitis to develop an educational intervention.

Materials and methods

Design:

The purpose of this study was to explore the components of the lifestyle in patients with ulcerative colitis in order to develop a particulareducational package for them. Hence, the study design was a qualitative design with in-depth interviews based on the phenomenological method.

Participants and procedure:

The participants were recruited using purposeful sampling from the IBD outpatient clinic of Isfahan University of Medical Science and private office. The purpose of selecting contributors in phenomenological research is selecting subjects with experiences that are noticeable in this particular study and the participants are eager to talk about them. In addition, as far as possible these contributors should be different from each other to provide a rich and unique narrative about a particular experience (19).Thus in this study, the sampling was done in such a way as to ensure the greatest variation in diagnosis and duration of UC, age, and sex. Subjects with UC, within the age range of 18-70, and the ability to express thoughts and feelings, and with appropriate physical and mental ability to participate in the interview were included in the study, and the subjects who had psychiatric disorders (such as bipolar disorder and severe depression), and lack the motivation to participate in the interview were excluded from the study. Interviews were conducted with 28 patients, but it should be noted that after 24 interviews,

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new information was not added and the last 4 interviews were done to ensure data saturation. Because of the apparent lack of voice of the two interviewees, they were excluded from the research and analysis was done on 26 patients. Interviews were conducted over the course of 2 months and lasted for an average of 40 minutes (range: 19–68 minutes). The first author conducted all interviews, 20 in private office and 8 in IBD clinic. The interviews started with one open-ended question: Could you please describe your experiences about UC disease? (its effect on your lifestyle and the changes that occurred in your lifestyle?) In order to encourage the participates to elaborate on and explain their lifestyle different probing questions were applied.The questions (related to the components of lifestyle)were inquired based on the interview process and interviewees' responses.

Informed consent was obtained from each patient for the participation in the interview. Meanwhile, the interviewees were assured that all of the datapresented in the interviews would be confidential and they can refuse to participate in the interview whenever they like. Ethical approval was obtained from the University Ethics Committee. After all interviews were carried out and digitally recorded, the researcher listened to the recorded files and transcribed verbatim them. At the end, data were analyzed using seven-step Colaizzi method (20).To ensure the rigor of the research findings, four criteria of credibility, trustworthiness, transferability, and conformability were met.

Results

A total of 26 UC patients, 14(54%) females and 12(46%) males, with mean±SD age of 39.41 ± 11.8 years (females: 41.07 ± 13.72 yearsand males: 37.45 ± 9.33 years), 15 (57.6%) graduated from university, 22(84.4%) married, mean duration of disease=7.56 years, and mean age of disease=31.29 years were included in the study. The qualitative analysis of data was summarized in four main concepts and nine components. The conceptual model of lifestyle and how to communicate its concepts and components with each other are depicted in Figure (1).

The new discovered components are described using descriptive quotes from participants in the research:

- **Stress.**The majority of participants emphasized on the experience of continuing stress and its impact on their disease and vice versa. They stated that their situation gets worse with any stress, even small.Quote: "With any stress, my symptoms return rapidly and I get bleeding …" (No. 5).
- **Emotions**.The negative emotion experience was reported by most of participants. Quote: "..... When my body has a problem and I feel pain, it affects my mood. My impatience is most often related to the disease." (No. 21).
- **Coping Strategies**.Some of the coping strategies utilized by the patients to manage stress and to regulate their emotions were efficient while others were not. Quote: "I have a lot of negative thoughts, some bad memories are always in my mind and I couldn'tget rid of them..." (No. 7).
- **Physical activity**.Most participantsdid not have regular exercise practices for various reasons, for example,UC symptoms. Of course, men had more athletic practices than women. Quote: "I'm not active at all. Doctor said me: do mild exercise, but I do not do, also I'm not walking...." (No. 11).
- **Nutrition**.Participantsmostly believed that another important factor associated with the disease is nutrition, since their symptoms get worse by eating unhealthy foods and it leads to the recurrence of the disease. However, food limitations or modifying eating behavior was difficult for them. Quote: "Doctor tells me that you need to live like old men. Well, this makes me sad " (No. 15).
- **Sleep.** Regardless of the impact of the disease on sleepquality due to the need for frequent waking in

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the stage of the disease activity, some participantscomplained about insomnia. But their sleep patterns had more problems: Quote: "I cannotchange this lifestyle, for example, I decide to sleep at 11 o'clock, to put my bad habits asideand to replace some good habits, but I can do it only for one week, ….., due to lack of motivation "(No. 17).

- **Positivity** .When participantswere talking about their experiences, some of their experiences were about hope or disappointment, optimism or pessimism, ability to resilience, satisfaction… Quote: "I am positive about the future, especially when my disease is silent or under control. I was not hopeful before "(No. 8).
- **Spirituality**. Participantsintroduced experiences that were related to spirituality and its various dimensions. Quote: "I believe that this disease is God's demandfor me, good or bad .... I must get used to it and live with it. I'm not so upset about why this happened to me….. (No. 22.)
- **Strict Standards**. Nearly all participantsnoted that they have strictstandards in doing their daily routines. Quotes: "I think I'm very idealist,…because I must do anything perfect or I don't it at all. There is no average." (No. 17). "I liketo be good at work, I try, I spend so much time, …" (No. 23).
- **Interpersonal Relationships**. Most the participantsdid not have effective communication skills to interact with others. Lack of the skills and inefficient communication styles exacerbated their emotional problems or distress. Quote: "I cannot say no to customer, and this creates stress for me " (No. 16).

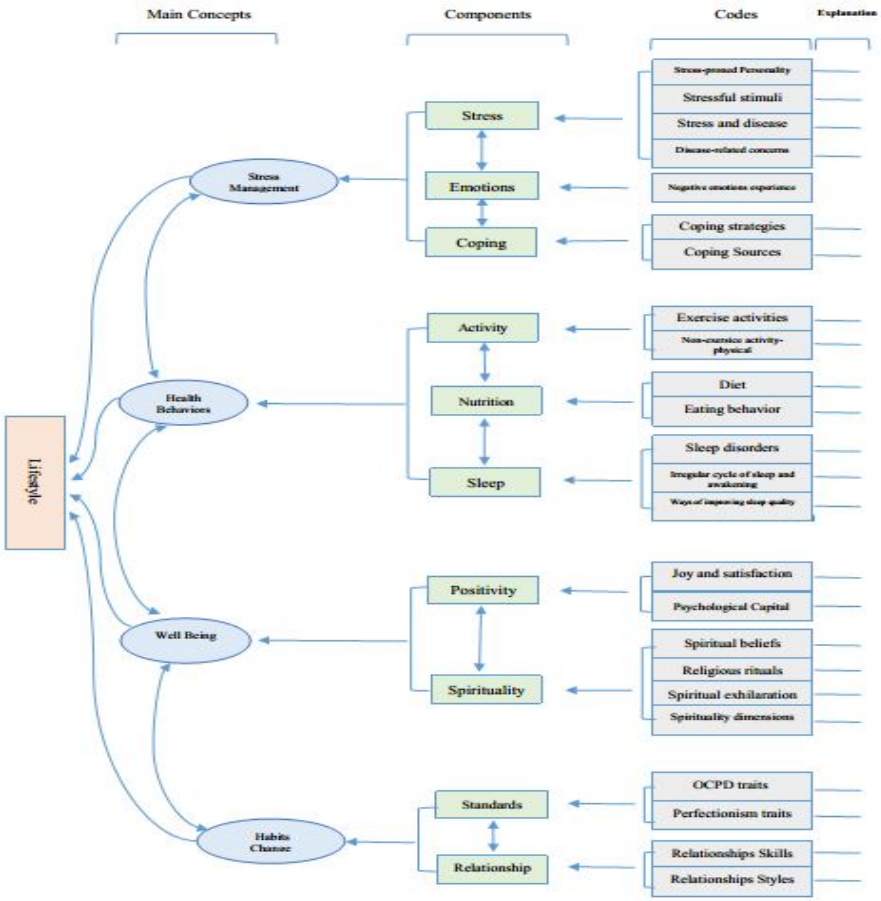


Figure 1. The Conceptual Model of Lifestyle Educational Package in UC Patients

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Discussion

One of the experiences that most patients point out was the relationship between stress and the disease symptoms. On the other hand, patients' experiences indicate that they do not have a proper stress management in most cases during their lifetime. Therefore, this issue put forth the need to address stress management since individual stress management style is important for preventing and controlling various stressors and improving health. Various studies have been conducted on patients with IBD in recent years (21, 22, 23, 24). Their findings indicated the positive effect of stress management on improving psychological problems and reducing physical symptoms in some cases. Another issue is that the psychological response of the subjects who receive diagnosis of a particular disease, such as a chronic disease, is discomfort and suffering. Hence, anxiety, depression or sadness, irritability and anger, and particularly disease related concerns and worries that were experienced in different varieties are in line with previous studies (22, 25, 26, 27). There is a strong correlation between the negative emotions (25, 28, 29) and patients' quality of life (30) which can be managed by using emotion regulation techniques. Although in the present study, patients used both adaptive and maladaptive cognitive coping strategies in dealing with different issues, when symptoms appeared or the disease became active, ineffective strategies became more and more active, or the use of effective strategies was reduced. These findings are in line with the research conducted in this regard (12, 31, 32). Subjects who use maladaptive cognitive coping strategies are more likely to experience stress (33). Effective coping strategies help a patients to adapt to bad and harmful stressors and consequently lead to clinical outcomes and lifestyle satisfaction improvements (34). In fact, people who use emotion regulation adaptive cognitive strategies when they are stressed can effectively manage their emotional intensity and increase their resiliency, by changing their evaluations (35).

With regard to health behaviors, patients were heterogeneous in terms of physical activity and face some limitations. In line with other studies, despite an acknowledgment of positive effect of exercise on their mood or physical condition, most UC patients did not make regular exercise as a part of their daily routine as a positive behavioral habit (36). It's noteworthy that limited information is available on the exact amount of needed exercise (37) and to create optimal types, duration and intensity of exercise for IBD patients, more research is needed. Meanwhile, moderate-intensity exercise has beneficial effects on the immune system and can neutralize some of the complications of IBD by improving bone density, muscle mass and strength, quality of life, health nutrition and psychological well-being (36). Self-efficacy, perceived behavior control and enjoyment are the key factors in a healthy physical activity (38). Natural sleep is of utmost importance for a healthy lifestyle and high quality of life (39). Sleep problems of patients were categorized into three categories: disease activity or symptom related, unrelated to the disease's activity, and the unfavorable cycle of sleep and awakening. Sleep disturbances in IBD patients have been confirmed in other studies (16, 39, 40), about half of the patients experience sleep disorder and lower quality of life (41). Abnormal sleep patterns (39, 40), inadequate sleep or sleep deprivation (39, 40), and impaired sleep quality or long or short sleep periods (41) can be major risk factors for IBD. A healthy sleep and wakefulness cycle is critical to regulate the immune system and the neuroendocrine system. Hence, the problem of sleep disturbance should be considered in the clinical management of IBD patients (40). Another factor in preventing lifestyle related diseases is nutrition. In fact, nutrition and diet were amongst the main concerns of the patients. Some of them thought that nutrition was a major factor in initiating or heightening

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of the UC symptoms. In this regard, a large body of scientific evidence supports the role and the importance of nutrition in maintaining the health of UC patients (42, 43). Although most dietary instructions (diet type, nutritional habits, and eating behavior) are general recommendations that all individuals should follow, there are some issues that are emphasized in patients with ulcerative colitis. Educational sessions can provide patients with the necessary information.

In terms of psychological and spiritual well-being, the experiences of patients indicate that irrespective of everyday life events, when ulcerative colitis is activated, its consequences can influence positivity and psychological capital of them. Happiness, life satisfaction, hope, optimism, self-efficacy and especially resilience are psychological abilities, that some of the patients show lower levels of them. The chronic, periodic and untreatable course of the disease, the need for continuous care, the unclear nature of the disease, the risk of cancer or other complications, sometimes makes patients anxious, sad, and ultimately disappointed and reduces the above mentioned abilities in them. According to Seligman, the unpredictable and incurable course of the disease impairs individual's belief about self-control and self-efficacy (44). Therefore, patients need to strengthen their motivation to build hopefulness, having an active life, and participating in their own treatment process. The positive traits and abilities of the individuals can contribute to their development. Hope and optimism are among these abilities (45) that should be considered in these patients. Given that diseases, in particular chronic diseases, have many physical, psychological and social effects, they can also result in helplessness in these patients, so they might begin to turn away from materialistic factors because of hopelessness and turn toward religious activities. Of course, this is not true for all patients, and some do not realize the effect of this spiritual relationship. Our findings involve a wide range of spiritual experiences in patients. One of these experiences was in the form of spiritual beliefs. Having spiritual beliefs is an effective way to cope with the acute and chronic problems of life, especially with regard to the disease and its consequences. These beliefs not only increase a healthy sense of psychological wellbeing through creating a sense of purposefulness in patients, but also increase their tendency to create favorable changes in the lifestyle (1). Other spiritual experiences of the patients pertained to religious ritual, spiritual exhilarationand dimensions such as gratitude, forgiveness and meaning. Creating and maintaining spiritual health plays an important role in adapting to stress. In other words, coping styles are stronger in people with spiritual experiences and beliefs (46). Studies show that interventions in which therapist teaches spiritual concepts to clients and relates these concepts to their situations are more effective (47).

In terms of habits change, one of the issues was the existence of strict standards that patients set for their various tasks and habitually adhere to it. The concepts obtained in this regard demonstrates the presence of obsessive-compulsive and especially perfectionism traits which is consistent with the findings of Robertson et al. (1989) (48). Perfectionism means the determination of very strict and self-imposed criteria, and despite the fact that create problems, the individual is struggling to achieve them (49). Ulcerative colitis can cause limitations for patients especially in the active period of the disease, and create more difficulties in the process of criteria or goals attainment. Subsequently, they are likely to perceive more stress because they want to reach their previous level of performance, which may not be possible for a long time due to the disease complications, while this can worsen their physical and mental situation. Felt et al. (2011) found that perfectionism is linked to the use of maladaptive coping (emotional rumination) strategies and has greater impact on the disease (50). However, a chronic disease requires

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a new lifestyle in dealing with different things in order to decrease the level of stress. Patients' communicational experiences were more common in either aggressive or passive styles, andlack of some communication skills (inability to express feelings, being introvert, inability to ask, saying no, etc.). Assertive behavior was less reported. Hence, one of the issues that set the stage for stress and emotional distress in interpersonal relationships and in the workplace was the weakness in their relationship with others. This result was consistent with previous research. They indicated that inability to express proper anger or aggression is a common feature in IBD patients (48) and emotional expression is low especially in relation to negative emotions. Moreover, there is usually a high level of social agreement and a low level of assertiveness in patients' interpersonal communications (2). In fact, patients pursued a particular ineffective individual communication style that created tension in their life and in turn heightened the possibility of recurrence and subsequent mental issues.

The strength point of this study is the relatively large number of patients (n = 26), as the sample size in qualitative research is usually smaller. The limitations include in no similarity of patients in terms of the intensity of the disease activity and the type of UC disease (UC has 4 type based onextension in small bowel). Although the patients' subjective perception is assessed, both of them may likely create different level of difficulties for UC patients.

Conclusion

With the discovery of nine main components in relation to UCpatients' lifestyle, a lifestyle-based educational package can be developed for them. In the previous studies on IBD patients, stress managementrepeatedlyand health behaviors especially nutrition have been considered; the concept of well-being (psychological and spiritual) has rarely been directed to as an educational component (especially in relation to spirituality);but, the concept of habit change in the aspects of strict standards and interpersonal relationships as an important educational component has not received enough attention.Now, based on the obtained components, a lifestyle educational package can be developed and its effectiveness can be evaluated as a clinical trial on the UC patients, also the results can be compared with other psychological interventions performed on these patients.

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Conflict of interest. There is no conflict to declare.

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