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Original Article

Lifestyle-Based Intervention and Experiences of Patients with Ulcerative Colitis: A Concurrent Embedded Mixed Methods Design

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Abstract

Introduction: In the past two decades, there has been a growing line of research on the possible effects of psychological interventions on patients with inflammatory bowel disease (IBD). This study aimed to evaluate the qualitative validity of a lifestyle-based intervention in patients with ulcerative colitis (UC) by examining their experiences.

Methods: This study employed a concurrent embedded mixed methods design. To this end, a qualitative study was conducted in the form of a clinical trial that applied a lifestyle-based intervention to patients with ulcerative colitis. The patients' experiences were assessed twice through the focus group interviews. The data from both interviews (posttest and follow-up phases) were analyzed using thematic network analysis.

Results: Based on the results of this study, 3 global themes, 10 organizing themes, and 21 basic themes were identified and summarized in three thematic networks of benefits, barriers, and disadvantages. Benefits included satisfaction with attending the meetings, knowledge acquisition, cognitive, emotional, and behavioral changes, and partial physical improvement; barriers included physical symptoms, need for retraining, giving importance to the topic, and restrictions in physical activities; and the disadvantages included the negative impact of the group and the negative impact of the training program.

Conclusion: The results of this study confirmed the qualitative validity of a lifestyle-based intervention in a group of patients with ulcerative colitis by demonstrating the educational and therapeutic effects of the intervention and its acceptability.

Keywords: Ulcerative colitis, Lifestyle, Concurrent embedded design

Introduction

Inflammatory bowel diseases (IBD) include ulcerative colitis and Crohn's disease as the two main chronic and recurrent diseases that cause chronic inflammation of the mucous membrane and the increased intestinal permeability (1). The physical, psychological, and occupational functions and the quality of life of people with chronic diseases are affected by the disease (2). For instance, several studies have reported the profound impact of IBD on patients' psychological well-being (3). Therefore,

the treatment goals in IBD patients are to create and maintain remission (stopping symptoms for a long-term), reduce risk of complications, and increase quality of life (4).

Drug limitations are one of the concerns that have led researchers to look for other ways to manage symptoms and improve the psychological functioning of IBD patients (5). Alternative treatment approaches including psychological interventions may help harness the flare-up of the disease and improve the patient's psychological condition and quality of life. Evidence suggests that psychotherapy can have a significant impact on psychological and clinical outcomes (6). In fact, most psychological interventions have a positive effect on the emotional and psychological functioning and the quality of life of IBD patients (7). These interventions not only help patients overcome symptoms such as depression, anxiety, or other associated psychiatric problems but may also reduce the perception of stress and thereby reducing the number of recurrences or prolonging the recovery (8). However, a review of 18 studies showed that although psychotherapy promises to reduce pain, fatigue, relapse, hospitalization, and ultimately the stability of the treatment, it has little effect on anxiety, depression, the quality of life, and disease recovery (3). It has been reported that this inconsistency may be partly due to differences in trial designs, the components of treatment protocols, the outcomes of evaluated measures, and other disturbing variables (7). Usually, the effectiveness of psychological interventions is evaluated quantitatively and the lack of significant statistical results regarding the variables studied indicates the ineffectiveness of the intended treatment. However, the qualitative results of such interventions are rarely evaluated. Although the statistical significance is important in terms of the cost-effectiveness of such sessions, patients' own experiences are also important because questionnaires sometimes are not able to accurately measure the efficacy of a therapeutic approach and the extent to which the participants benefit from it. On the other hand, the researcher's goal may not be aligned with the patient's impression of the treatment sessions.

Lifestyle is the target of a line of research that can play a significant role in the prevention and management of inflammatory bowel diseases. Therefore, the present study aimed to evaluate the effects of a lifestyle-based intervention on the experiences of patients with ulcerative colitis. A deep understanding of patients' experiences can help the researcher to evaluate further the effectiveness of the training package and measure its validity. Such an evaluation process within a trial can provide insight into the effectiveness of the intervention and its potential benefits for patients. Accordingly, the present study aimed to evaluate the qualitative validity of a lifestyle-based intervention applied to UC patients.

Methods

In this study, a mixed research method with a concurrent embedded design was employed to evaluate and understand the experiences of patients with ulcerative colitis of a developed lifestyle training package. In this design, both quantitative and qualitative methods were implemented simultaneously. The quantitative method was conducted as a clinical trial in 10 weekly group training sessions and the qualitative method was incorporated into the clinical trial. The collected data were analyzed separately (the quantitative findings were reported in another article). In the embedded design, the participants selected for one phase of the study (qualitative) are a subgroup of participants selected for the other phase of the study (quantitative). The sample size in the quantitative phase was initially 18 patients who were voluntarily selected, but a total of 7 participants attended the training sessions. Accordingly, the interviews were conducted with 7 patients who had experienced the intended phenomenon, namely the lifestyle-based training intervention. The interviews were conducted and recorded after obtaining the informed consent of the participants. Besides, the interviewees were assured all the interview data would be kept confidential and they could refuse to participate in the interview at any time.

Even though the survey from patients about the effectiveness of each session was on the agenda for the next session, there were two focus group discussions (the posttest and quarterly follow-up) for the validation of the lifestyle training package. To this end, the group focused on a group discussion to investigate a particular issue (9). The interview started with an open-ended question "How did you find attending the training sessions?" and the subsequent questions were asked based on the answers provided by the interviewees. Moreover, the probing questions were asked to further explore the participants' experiences. All participants' conversations were recorded. To encode, the audio texts were first transcribed verbatim by listening to the recorded files and then the extracted data were coded.

Thematic network analysis was used to analyze the data (10). In this analysis, thematic networks are

formed to explore the understanding of a topic. In fact, the thematic analysis seeks to discover the themes salient in a text at different levels and thematic networks are used to facilitate the structuring and depiction of these themes. Thematic networks summarize the extracted data into three types of themes: 1) Basic themes that represent the most basic themes derived from the textual data, 2) Organizing themes as middle-order themes that organize the basic themes into clusters of similar themes, and 3) Global themes as higher-order themes that encompass the main metaphors in the text as a whole. Every global theme is the core of a thematic network. Thematic networks are displayed as web-like maps highlighting the salient themes at each of the three levels and illustrating the relationships between them. In the present study, all extracted themes were reviewed several times and after evaluating the accuracy and robustness of the data, the experiences gained from the lifestyle training package were formulated in the form of three thematic networks that show in what aspects this training program was more effective. To guarantee the accuracy of findings, four criteria of credibility, trustworthiness, transferability, and confirmability were met (11).

Results

In this study, 7 female UC patients with the mean age of 36.14±7.6 years attended a 10-week lifestyle training course. Their characteristics are shown in Table 1.

The data obtained from the participants' experiences of the training package were analyzed through a six-step thematic network analysis as follows:

Step 1: Coding the material: At this stage, 40 codes were derived based on a combination of specific topics or words related to the patients' experiences and important topics repeated in the data. By examining the transcripts, more prominent constructs were identified and placed within a limited set of codes that were sufficiently meaningful and separate from each other, and then the transcripts were categorized and organized according to these codes. For example, "Acceptance" was classified as a code containing textual data such as "I tried to be receptive to issues that bothered me and I couldn't change them".

Step 2. Identifying themes: A total of 40 codes were divided into 21 clusters and each of the textual data related to the code were re-read. The most prevalent themes were given priority. This provided the possibility to focus on the common themes that were of particular interest in this study. Another analysis was performed on individual narratives that dealt with different criteria for selection, for example, specific themes related to a person.

Step 3. Constructing the networks: This stage consisted of six steps:1) 21 themes were arranged according to the related conceptual content, 2) 21 basic themes were reduced to 10 groups based on conceptual similarity, 3) 10 groups of basic themes were named as organizing themes, and the common topics of the basic themes were identified, 4) Three global themes were obtained by unifying the organizing themes, 5) The findings were illustrated as three separate thematic networks, and 6) The networks were reviewed and adjusted based on the data.

Step 4: Describing and exploring thematic networks: The thematic networks represent an exploration of the participants' conceptualization of the benefits, barriers, or disadvantages of attending the training sessions. This stage represents a remarkable analytical step to the interpretation at a level beyond summarizing. In this stage, the networks were examined in more detail.

A. Thematic Network of Benefits

The main benefits of the lifestyle learning package assessed by the UC patients were categorized into 4 organizing themes and 10 basic themes (Figure 1).

1. Satisfaction with attending the meetings

General statements: The majority of participants (86%) found that the training sessions were positive and useful. They stated that lifestyle training has helped cope with emotions, relax, practice health-promoting behaviors, and enhance skills (Participants 1, 3, and 6).

Table 1. Participations' characteristics

No	Age	Disease duration (year)	Martial status	Education	Job
1	31	5	Divorced	Bachelor of arts	Tailor
2	27	2	Single	Bachelor of science	Employee
3	31	8	Married	Associate degree	Homemaker
4	44	30	Married	Bachelor of arts	Teacher
5	41	12	Married	Middle school degree	Homemaker
6	47	10	Married	Associate degree	Homemaker
7	32	2	Married	Bachelor of arts	Homemaker

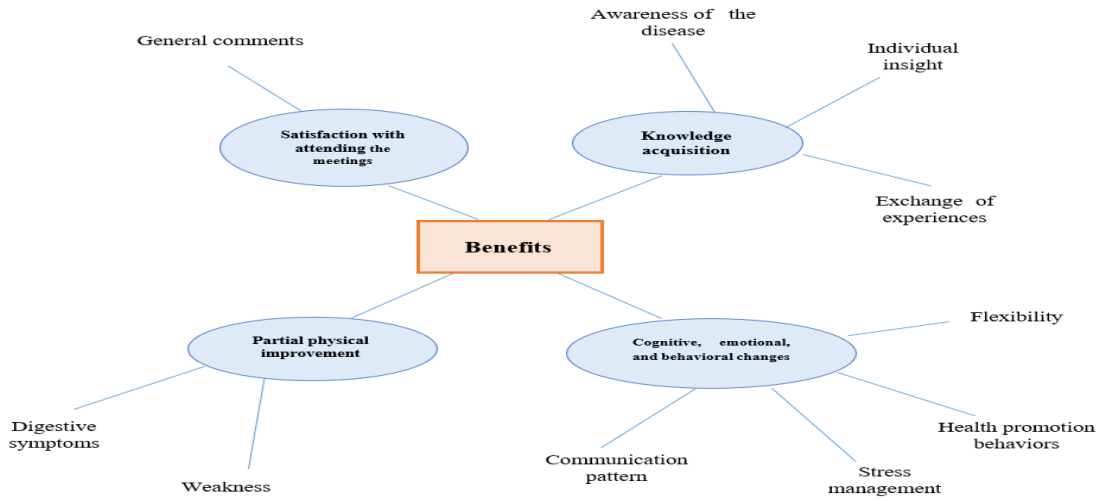

Figure 1. Thematic Network of Benefits

2. Knowledge acquisition

- Awareness of the disease: One of the other outcomes of the training sessions was to obtain information about the nature of the disease and some other aspects including the role of nutrition in the disease. One participant stated that she was unaware of the nature of the disease and did not know that the disease needs follow-up measures due to its chronic nature (Participant 4). Another participant stated that the meetings provided useful information for her especially regarding nutrition (Participant 7).
- Individual insight: It appears that the participants' insight about themselves were to some extent enhanced by the meeting. One participant stated that she understood those personal aspects that needed to be changed further (Participant 6).
- Exchange of experiences: During the sessions, the participants were allowed to express and share their views on topics discussed by others. These comments were shared as recommendations on nutrition, medication acceptance, or follow-up measures (6 Participants).

3. Cognitive, emotional, and behavioral changes

- Flexibility: The training package was able to help nearly 70% of the patients to make changes in their functional and dysfunctional cognitive strategies and show greater cognitive flexibility in dealing with problems (Participant 1,2,3,6, and 7).
- Health promotion behaviors: The participants stated that they often had digestive symptoms or weakness after eating some foods, which led to fear and anxiety about eating different foods or induced some concerns in this regard. In the sessions, they not only learned nutrition is specific to each patient and found out the way they could overcome their fears and anxiety, but also realized the way one eats (eating behavior) is related to the appearance of symptoms (Participants 1 and 7). For one participant, beginning to enjoy eating was a significant therapeutic experience (Participant 6). In addition to nutrition, some participants experienced changes in two other factors i.e. sleep and physical activities (mainly walking) (Participants 1,4,5, and 6).
- Stress management: Some participants stated that after attending the sessions and applying trained techniques, they were able to manage their stress and negative emotions more effectively (Participants 1,2,3, and 6).
- Communication pattern: Another aspect in which participants (over 50%) reported behavioral changes was the change in communication style, moving towards having an assertive style, and gaining experience about communication skills. These changes were mainly related to the skills of saying "no" and expressing emotions (Participants 1,2,3, and 7).

4. Partial physical improvement

For some participants, this intervention resulted in partial alleviation or continuation of recovery of physical symptoms.

- Weakness: Two participants stated that attending the classes and applying some techniques (especially concerning nutrition) could help them to reduce their weakness to some extent

(Participants 1 and 2). Besides, two other participants gave a general report of having no weakness or decreased weakness, despite complaining about it at the beginning of the sessions (Participants 3 and 4).

- Digestive symptoms: Some participants commented on the impact of the training program on their physical symptoms. One stated that, despite having a high level of stress (during training), her disease was not activated and remained silent (Participant 3). Another stated that her focus on and sensitivity to physical symptoms disappeared (Participant 1). A third participant expressed that, despite having symptoms during the course of training, her physical conditions improved (Participant 2).

B. Thematic Network of Barriers

The obstacles to the implementation of the tasks and applying techniques and training were also discussed which were categorized into 4 organizing themes and 7 basic themes (Figure 2).

1. Physical symptoms

Disease activity: According to the participants, attending meetings or doing practices as well as sports activities especially participating in sports clubs as one of the necessary changes in the lifestyle of the patients were deterred by some obstacles. One participant reported physical symptoms and especially weakness (participant 7) as the reasons for not attending the two missed sessions. The same participant stated that one of the barriers to homework assignments was the symptoms of the disease activity.

2. Need for retraining

Based on the participants' experiences, making changes in the lifestyle and applying training based on the three basic themes (need for repetition of contents and exercises, difficulty to change, need for an opportunity) are difficult and need repetition and the lapse of time (Participants 1 and 6).

3. Giving importance to the topic

Involvement: Another obstacle to implementing homework assignments and making them more applicable to the participants' life was their involvement and occupations. This made them attend sessions only for theoretical knowledge acquisition, and the application of this knowledge required more understanding of the importance of the topic (Participant 4).

4. Restrictions in physical activities

Regarding doing physical activities or performing them more regularly by participating in sports clubs and being a part of the group, participants had limitations either in individual sports (Participants 4,6, and 7) or the club sports (Participants1,6, and 7): individual restrictions and club restrictions.

- Individual restrictions: One of the limitations that patients expressed about having a daily walking program was their busy lives and especially their feeling of weakness.
- Club restrictions: None of patients were willing to participate in the club because they did not have good experience in this field and they did not consider these exercises suitable for their condition due to their weight and pressure.

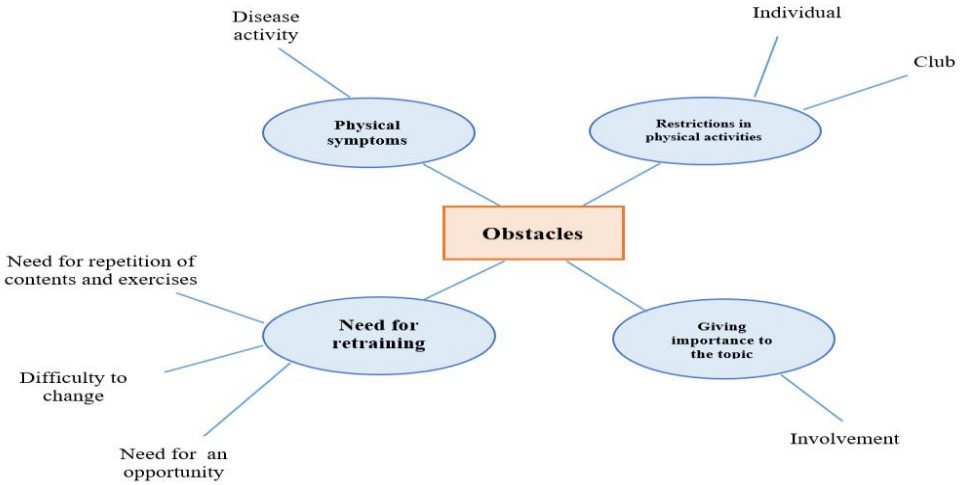

Figure 2. Thematic Network of Obstacles

C. Thematic Network of Disadvantages

A small part of group discussions was about the disadvantages of attending training sessions, which were categorized into 2 organizing themes and 4 basic themes (Figure 3).

1. The negative impact of the group

- Stopping medication: One participant stated that she was tempted to stop taking medication because of another participant's avoidance to take medications (Participant 5).
- Negative emotions: One participant stated that talking to other patients about their disease demoralized her and after that, the symptoms of the disease reappeared (Participant 2). Another participant said that the disease did not matter for her so much as others were exaggerating about it, but she was worried when she talked to others (Participants 4).

2. The negative impact of the training program

- Disappointment: One participant stated that she hoped to recover from the disease but when she realized its nature, she ended up in disappointment (Participant 7).
- Worry: One participant stated that some of the questions in questionnaires concerned her (Participant 1) and another participant expressed that excessive awareness of the disease overwhelmed her.

- **Step 5: Summarizing the thematic networks:** In this study, three networks were developed each including a separate conceptualization. In the first network, "benefits" is at the center of the network marking a distinction between satisfaction with attending the meetings, knowledge acquisition, cognitive, emotional, and behavioral changes, and partial physical improvement and the main point is that training sessions can have different (not the same) effects for participants. In the second thematic network, "barriers" is at the center of the network making a distinction between physical symptoms, the need for retraining, giving importance to the topic, and restrictions in physical activities and the main point is that the effectiveness of training sessions may encounter some barriers depending on the circumstances of the participants. Finally, in the third network, "disadvantages" lies at the center of the network making a distinction between the negative impact of the group and the negative impact of the training program and the main point is that training sessions can be accompanied by some disadvantages.
- **Step 6. Interpreting patterns:** At this stage, the researcher linked the main themes and patterns discovered in the research question. Accordingly, the results of the study are in line with the research question. The overall pattern illustrates the validity of the lifestyle training package (Figure 4).

Discussion

The main objective of the present study was to explore the experiences of patients with ulcerative colitis of participating in lifestyle training sessions and also provide evidence for the qualitative validation of the training package. The network analysis of the qualitative data revealed three global themes and several lower-level themes. In this regard, two studies performed on patients with inflammatory bowel disease used a concurrent embedded design in a way relatively similar to this study (12,13). Schoultz et al. identified three main themes that included benefits, obstacles, and expectations of the treatment process (12). This finding is in some ways consistent with the results of the present study. The themes extracted in this study included benefits, barriers, and disadvantages.

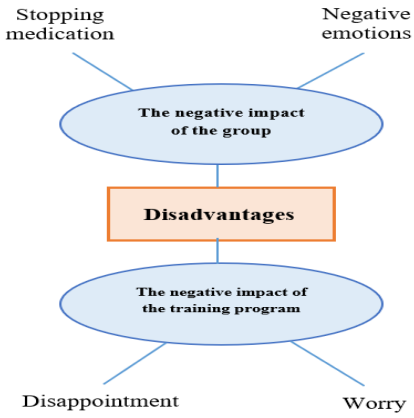

Figure 3. Thematic Network of Disadvantages

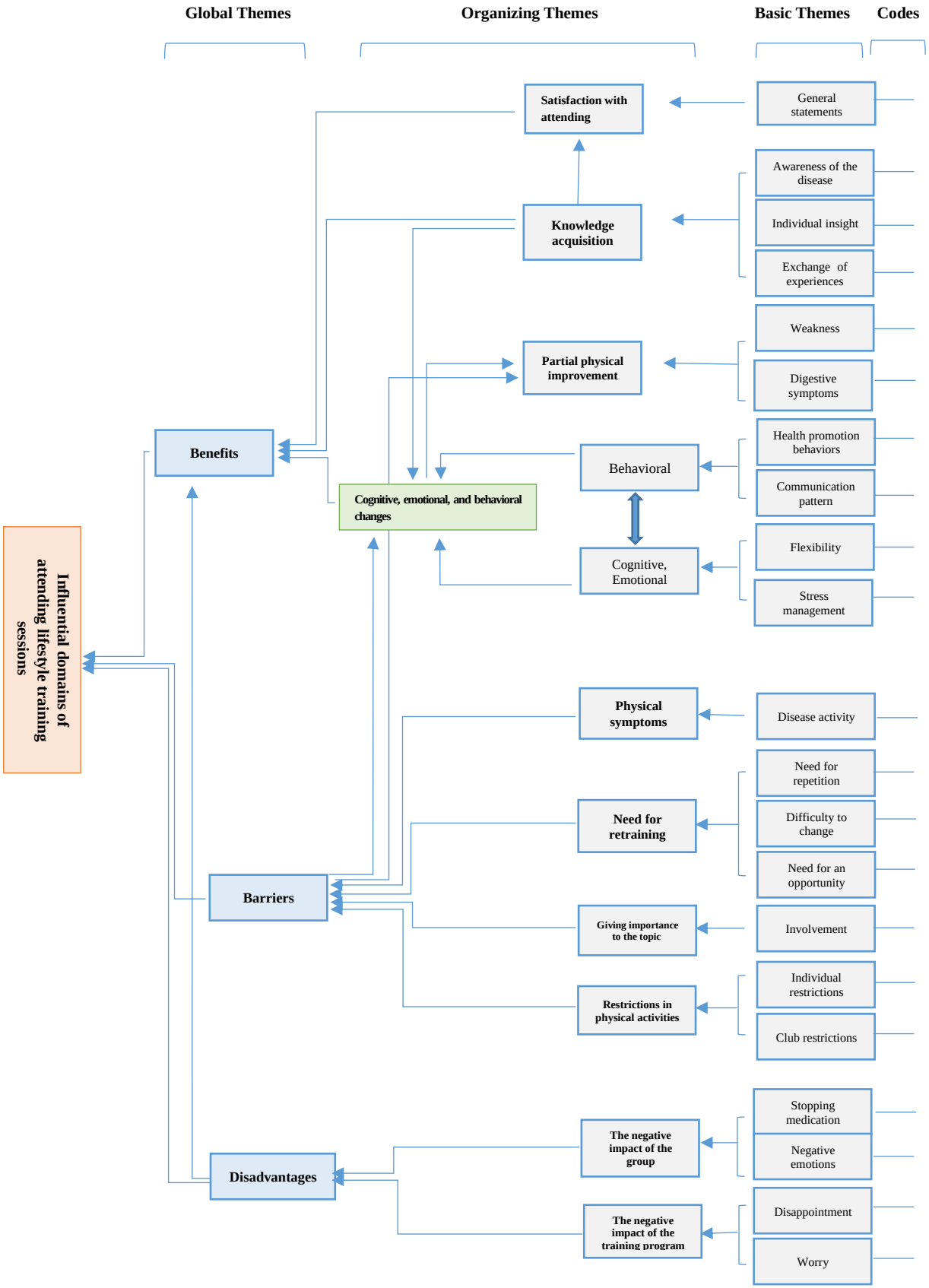

Figure 4. The overall pattern obtained from the validation of a lifestyle teaching package

The participants expressed satisfaction with attending the lifestyle training sessions and talked mainly about the benefits of the training and its effect on their behavior. The benefits included 4 themes of satisfaction with attending the meetings, knowledge acquisition, cognitive, emotional, and behavioral changes, and partial physical improvement pointing to the effectiveness of the training sessions on the patients. In the same vein, Schoultz et al. identified three therapeutic, educational, and inclusive themes that illustrate further the more general domains of the effectiveness of mindfulness-based therapy (12). The majority of patients made general statements about the effects of lifestyle intervention on their actions and behaviors. Their personal experiences showed that attending the sessions not only had educational benefits, but also made changes in their psychological and behavioral aspects. Accordingly, the effectiveness of lifestyle-based training has been confirmed in other clinical studies (14-16). Changes were created in the four dimensions of flexibility, health promotion behaviors, stress management, and communication patterns. These changes were in line with the aims of the training package. Besides, these changes were in line with the findings of Schoultz et al. (12) showing the therapeutic benefits of psychological interventions in UC patients. These findings are also consistent with other lifestyle-based researches on IBD patients (17,18) and other chronic physical diseases (14-16). One of the therapeutic goals of psychological interventions in chronic physical diseases is to reduce or eliminate physical discomfort and suffering. According to the participants, there was some improvement in their physical symptoms especially fatigue or preventing disease relapse despite having stressful conditions during the training period. This finding is in line with research findings by Garcia-Vega et al. and Vogelaar et al. (19,20). The results of a qualitative study by Schoultz et al. confirmed the results of the present study indicating that psychological interventions can have therapeutic effects on physical symptoms (12). Another benefit was obtaining information about the disease and its nature, personal perception or better self-care techniques. Awareness drives patients toward the way they can deal with their different needs and makes them always look for ways to solve their problems. Various studies have found that knowledge acquisition is a complex cognitive process of perception, learning, communication, attachment, and reasoning and is closely related to health behaviors. Accordingly, Cooper et al. stated that awareness of the nature of the disease is important, although it may be difficult to develop a sense of control and the ability to predict outcomes (21).

The effectiveness of this intervention was hindered by some barriers. There were limitations to doing assignments and the applicability of the pieces of training. This finding is in line with a study by Schoultz et al. (12), but the type of limitations or obstacles were different. In their study, the obstacles were mainly related to attending sessions (time and distance) but in the present study, the obstacles obtained were more related to the applicability of the training. These obstacles could potentially affect the impact of lifestyle training on some participants. Some studies, especially lifestyle-based research on inflammatory bowel diseases, have shown that the treatments have been less effective or ineffective in follows-up phases (17). In the same vein, the present study showed that if training program is supposed to become a part of one's lifestyle, there is a need for repetition and the continuation of training practices over a long period.

Apart from the benefits and barriers, the patients' experiences revealed the disadvantages of attending the lifestyle sessions. For instance, it was reported that obtaining certain information particularly about the disease may cause anxiety or other special concerns for some participants. Of course, the disadvantages of attending this series of training sessions were probably not specific to this type of intervention and could occur in IBD patients attending other training interventions.

As some volunteers could not participate in the quantitative phase of the study until the end of the training period (for various reasons, especially the relapse of disease symptoms or working conditions), one of the main limitations of this study was the small sample size that made it difficult to interpret and generalize the data.

Conclusion

The lifestyle intervention was shown to be able to make cognitive, emotional, and behavioral changes in patients with ulcerative colitis by promoting healthy behaviors, changing communication patterns, increasing the ability to manage stress, and flexibility. This finding is in line with the goals of lifestyle-based researches whose main purpose is to change the three dimensions mentioned above. The results of the integration of quantitative and qualitative data in the embedded design are summarized in Table 2.

Table 2. The results of the integration of quantitative and qualitative data

Quantitative results	Qualitative follow up interview to explain quantitative results	How the qualitative findings helped explain the quantitative results
Lifestyle training improved the mean posttest scores of all variables in question, but these changes were not significant compared to the control group. of course, the intragroup effectiveness of lifestyle teaching was significant concerning some variables	1- Satisfaction with attending training sessions 2- Become more empowered in stress management 3- Become more flexible 4- Change in interpersonal relationships 5- Paying more attention to self-health behaviors 6- Increasing knowledge about illness and self 7- Partial improvement in physical symptoms, especially fatigue in some patients	Despite the lack of significant evidence in the quantitative part of the study, changes in lifestyle in the patients' experiences and explanations were highlighted. The patients described their personal experiences about the developed package as an educational and therapeutic initiative that enabled them to make changes in themselves, gain awareness of the disease, and better manage outcomes. However, the barriers may have affected the effectiveness of this educational approach for some patients. In fact, the qualitative review indicates that the program is accepted in a group of UC patients.

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Conflict of Interest

The authors declare that there is no conflict of interests.

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