



The effect of web-based education on disease activity, symptom management and quality of life in patients with inflammatory bowel disease: randomized-controlled study

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General Note

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ABSTRACT

Background/Aims: The aim of the study is to determine the effect of web-based education on disease activity, symptom management and quality of life in individuals with inflammatory bowel diseases. **Methods:** This randomized controlled study was carried out with two groups that were web-based and standard education groups. The disease information was given either via website or educational books. **Results:** At the beginning of the study, it was found that the majority of the patients who were in the mild disease stage mostly entered remission during the study, however, there was no significant difference found between the groups in terms of disease activity according to measurement times. It was determined that there was a significant difference among severity averages of diarrhea, abdominal pain and faecal blood symptoms of patients in both two groups with regard to the time interaction. It was observed that there was no significant intra- and intergroup difference in terms of the quality of life scores of the education groups, but there was an improvement observed in the quality of life of the patients over time. **Conclusion:** In this study, there were no significant differences found between the web-based and standard education, however symptom severity, disease activity and quality of life were found to be improved in both groups. It was concluded that is structured or individualized education is effective and important.

Key words: Inflammatory Bowel Diseases, Web Based Education, Patient Education, E-Health.

1. INTRODUCTION

Inflammatory bowel diseases (IBD) that called Ulcerative Colitis (UC) and Crohn's Disease (CD) are chronic inflammatory diseases that can develop in various regions of the gastrointestinal tract, progress with remissions and exacerbations (Demirbulat, 2013; Frolkis, Dieleman, Barkema, et al, 2013; Hanauer, 2006). Based on the recent epidemiological data, IBD incidence and prevalence in the west were 8-14/100,000 and 120-200/100,000 for UC, and 6-15/100,000 and 50-200/100,000 for CD, respectively (Cosnes, Beaugerie, Carbonnel, 2001; Molodecky, Soon, Rabi, et al., 2012; Lichtenstein, Hanauer, Sandborn, 2009; Ozgursoy Uran et al. 2017).

The quality of life (QOL) of the patients is adversely affected due to many problems and symptoms experienced in IBD. Improvement of the QOL of the patient depends on the increased knowledge about the disease, ability to manage symptoms, disease activity, and medical treatment.

Web-based education is one of the areas in patient education and it rapidly becomes widespread in recent years. Today, the widespread use of internet on any subject, crowded hospitals, online registration for hospitals and online access to test results, availability of appointments for doctor examinations have led patients and their families to use internet for health problems (Demir, Gözüm, 2011). In various studies, it was emphasized that mobile health has increased, and web-based education and counseling services on many health problems have been found to have a positive effect on health outcomes (Avdal, Kızılcı, Demirel, 2011; Bennett, Herring, Puleo, et al, 2010; Heinrich, Nooijer, Schaper, et al., 2012; Rezailashkajani, Roshandel, Ansari, Zali, 2008).

In the European Crohn's and Colitis Organisation (ECCO)'s guideline, it is reported that there is a lack of knowledge in patients about their diseases, and therefore the decrease in QOL of patients is associated with the increase in their concerns and anxiety (Elkjaer, Shuhaibar, Burish, et al, 2010). Due to the impact of disease knowledge on the QOL, it is important for patients to reach the correct health information. Also with the effect of today's information technology, the question of "whether web-based education programs or face-to-face, standard education programs are more effective", therefore, constitutes the starting point of the research. The aim of this study was to compare the effect of web-based IBD Patient Education Program (IBDPEP) and standard education on disease activity, symptom management and QOL of patients.

2. METHODS

This randomized controlled study was conducted with IBD patients who applied to the gastroenterology unit.

Sample and Randomization

The sample of the research consisted of patients in the following:

- diagnosed with IBD at least six months ago,
- able to use computer, internet and mobile phone,
- aged 18 years and over.

Patients with advanced comorbid diseases such as cancer, diabetes, COPD, hypertension were excluded from the study since symptoms, disease activity and QOL would be affected at a different level.

In the analyses to determine the sample size, it was determined that there should be at least 26 patients in each group with 60% effect size, 80% theoretical power and with the reliability of 95%. However, considering the possible risks, a total of 60 patients, 30 in each group, were included in the study. For the selection of the education groups, simple randomization and stratified randomization were made separately according to the criteria of age, gender, educational level and duration of disease (Figure 1).

Randomization was made by a statistician; thus the researcher was blinded to the randomization process. It was ensured that the sample presented a normal or near-normal distribution and homogeneous variances in both groups.

As CONSORT criteria are now recognised standard for conducting and reporting randomised controlled trials, our design is reported according to these criteria (Moher, Schultz, Altman, 2001).

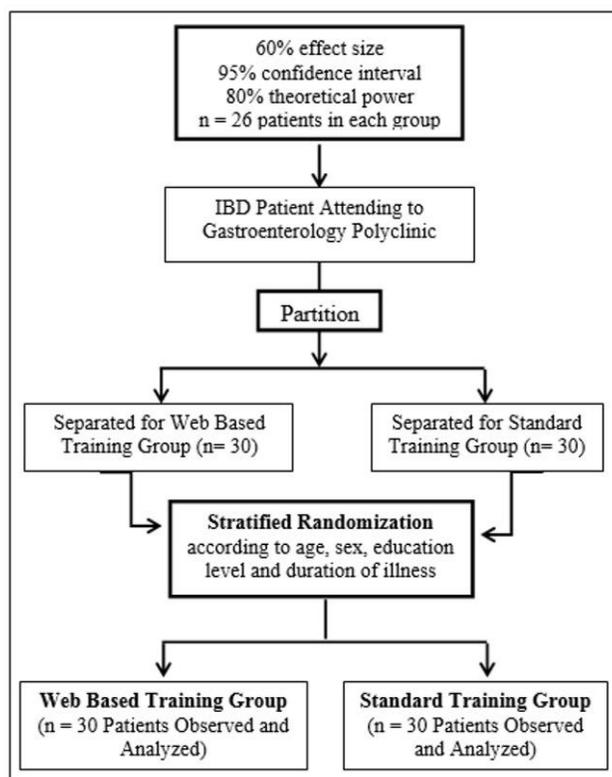


Figure 1: Randomization of Sample

Data Collection Forms

Patient Identification Form

It was prepared by the researcher in line with the literature and was composed of two parts, sociodemographic variables and disease-related variables (Cosnes, Beaugerie, Carbonnel, 2001; Rezailashkajani, Roshandel, Ansari, Zali, 2008; Elkjaer, Shuhaibar, Burish, et al, 2010; Moher, Schultz, Altman, 2001; van der Marel, Duijvestein, Hardwick, et al, 2009).

IBD Activity Indices

In the assessment of clinical activities, the Mayo Score was used for UC and the Harvey-Bradshaw Index was used for CD (Demirbulat, 2013; Lichtenstein, Hanauer, Sandborn, 2009; Truelove, Witts, 1995; Harvey, Bradshaw, 1980).

Control List of IBD GIS Symptoms

There is no IBD-specific "symptom checklist" in the literature (Elkjaer, Shuhaibar, Burish, et al., 2010; Moher, Schultz, Altman, 2001; van der Marel, Duijvestein, Hardwick et al., 2009; Truelove, Witts, 1995; Harvey, Bradshaw, 1980). GIS symptoms that were frequently reported by patients (diarrhea, abdominal pain, faecal blood, faecal mucus, urgent defecation, rectal sensitivity, nausea, and vomiting, decreased appetite and weight loss) were evaluated using visual analog scale (VAS). Patients were asked to rate the symptoms that they experienced in the last three months as "0 None" and "10 Unendurable".

IBD Quality of Life Scale (IBDQ)

IBDQ, which was developed by Guyatt et al., is a multiple-choice scale and is used to assess the QOL of patients with IBD (Guyatt, Mitchell, Irvine, et al, 1989). It was adapted to Turkish by Akçura et al. The Cronbach alpha coefficient is .95 and all item-total score correlations are significant ($p < .05$ and $r = > .50$). For this reason, the scale is valid and reliable (Akçura, Akpınar, Keskinoglu, 2013). The scale consists a total of 32 items and four sub-dimensions: bowel symptoms, systemic symptoms, emotional function and social function. Each question is scored from 1 "the worst case" to 7 "the best case". The score changes 32-224 points. The QOL of the patients increases as the score increases (Guyatt, Mitchell, Irvine, et al, 1989).

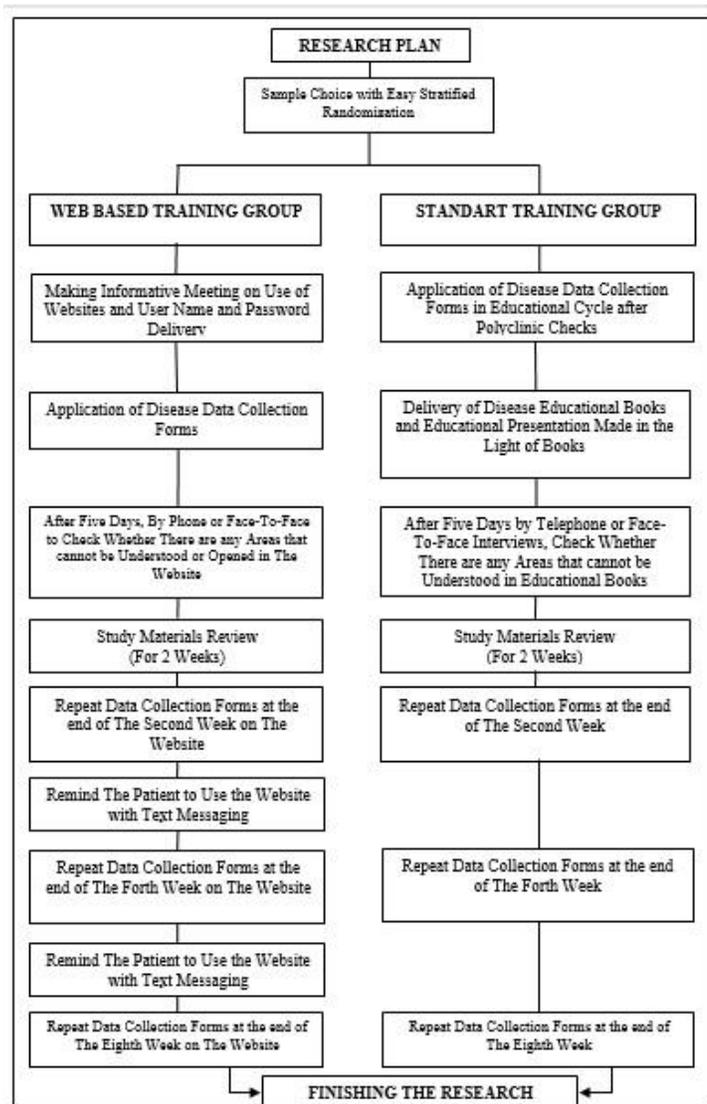


Figure 2: Algorithm Showing Research Plan

The Content of the Education Program for Patients with IBD (IBDPEP)

The content and scope of the web-based and standard education programs carried out with IBD patients were prepared to be exactly the same as each other by the researcher in line with the literature (Hanauer, 2006; Cosnes, Beaugerie, Carbonnel, 2011; Elkjaer, Shuhaibar, Burish, et al., 2010; Guyatt, Mitchell, Irvine, et al., 1989; Akçura, Akpınar, Keskinoglu, 2013; Lönnfors, Vermeire, Greco, et al., 2014; Peyrin-Biroulet, Loftus EV, Colombel, Sandborn, 2011; Mowat, Cole, Windsor, et al., 2011; Singh, Blanchard, Walker, et al., 2011).

Definitions, anatomy, and physiology, indications, diagnostic tests, treatment principles, the importance of drug use, nutritional principles, and specific descriptions for special cases such as pregnancy, sexuality and puberty are inclusively included in the content of the education. A website was designed for the web-based education group and all information was presented to the user with different interfaces. The standard education group received education via easy-to-read, illustrated, color-printed books.

Data Collection Process

The research plan that involves the methods followed by each group is shown in Figure 2.

Web-Based Education Group and Process

The first implementation of data collection forms to the patients in the web-based education group was made using face-to-face interview method, while subsequent implementations (2nd, 4th and 8th week) were made on the website. In the first interview, a username and password were

created for each patient and they were informed on how to use the website with a slide show. The 30 patients included in this study connected to the website a total of 415 times, and they reviewed the web pages 3480 times.

Standard Education Group and Process

All the data collection forms were implemented for the patients in the standard education group by face to face interview method. The education was given in a quiet, calm, bright education room with an appropriate temperature by sitting face to face with the patient at the same eye level. In the first interview of patients, data collection forms were implemented and the content of the educational books was explained with a slide show, then books were given to the patients. Patients in this group were recalled at 2nd, 4th and 8th weeks and data collection forms were implemented again. After each implementation, the educations that patients needed and were curious about were repeated and they were allowed to ask questions and express their concerns.

Statistical Analysis

The analysis of the study data was carried out using SPSS 16.0 programme. Kolmogorov Smirnov and Levene test for normality distributions, number percentage test for distribution of symptoms, t-test for comparison of severity averages, Spearman rank correlation analysis to examine the relationship between activity indices and QOL were made. The statistical results were assessed to be in the confidence interval of 5% ($p < .05$).

Ethical Considerations

Ethics approval was received for this study from the Ethics Committee of the Izmir Katip Celebi University (Decision Date/No: 13.08.2015/153). Animal and human rights statement, all procedures performed in this study were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. No animal or human studies were carried out by the authors for this article.

The participants' oral and written consents were received. Akcura also obtained permission for the use of the Turkish version of the IBD QOL.

3. RESULTS

Table 1 shows the distributions of the sociodemographic and disease characteristics of the patients. There was no significant difference between the groups.

Table 1 Sociodemographic and Disease Characteristics Distribution of Patients

Type of Education Characteristic	Web Based Education		Standard Education		Total		Test	p
	n	%	n	%	n	%		
<u>Sex*</u>								
Female	13	43.3	12	40.0	25	41.7	$\chi^2 = 0.069$.500
Male	17	56.7	18	60.0	35	58.3		
The average of age ($\bar{x} \pm$)*	37.26 \pm 12.99		41.63 \pm 11.85		39.45 \pm 12.52		t = 1.360	.179
<u>Education Status</u>								
Primary education	12	40.0	16	53.3	28	46.7	$\chi^2 = 1.294$.862
High school	11	36.7	8	26.7	19	31.7		
University	7	23.3	6	20.0	13	21.7		
<u>Marital status</u>								
Married	23	76.7	20	66.7	43	71.7	$\chi^2 = 0.739$.284
Single/ Separated	7	23.1	10	33.3	17	28.3		
<u>Number of children</u>								
No children	11	36.7	7	23.3	18	30.0	$\chi^2 = 3.378$.185
One children	10	33.3	7	23.3	17	28.3		
Two and more children	9	30.0	16	53.4	25	41.7		
<u>Job</u>								
Retired	5	16.7	7	23.3	12	20.0	$\chi^2 = 1.105$.576
Officer-Labor-Free	16	53.3	12	39.9	28	46.7		
Not working	9	30.0	11	36.7	20	33.3		
<u>Total Revenue</u>								
Less Income than Expense	10	33.3	13	43.3	23	38.3	$\chi^2 = 0.635$.298
Income Depot Equivalent / Excess	20	66.7	17	56.6	37	61.7		
<u>IBD Type*</u>								
UC	16	53.3	16	53.3	32	53.3	$\chi^2 = 0.000$	1.000

CD	14	46.7	14	46.7	28	46.7		
Disease Duration Average (month)*	82.23 ± 54.52		81.93 ± 56.71		82.08 ± 55.15		t = -0.021	.983
<u>Disease Age*</u>								
≤ 36 months	7	23.3	10	33.3	17	28.3	$\chi^2 = 2.889$.236
37–71 months	12	40.0	6	20.0	18	30.0		
≥ 72 months	11	36.7	14	46.7	25	41.7		
<u>Evaluation of General Situation</u>								
Very good	13	43.3	14	46.7	27	45.0	$\chi^2 = 0.067$.500
Under / Over	17	56.7	16	53.3	33	55.0		
<u>Fear of Cancer</u>								
Yes	23	76.7	19	63.3	42	70.0	$\chi^2 = 1.270$.199
No	7	23.3	11	36.7	18	30.0		

* Levene Test

t= Independent t Test

 $\chi^2 =$ Chi square Test

Evaluation of Patients According to Disease Activity

Table 2 shows the distribution of UC and CD disease activities of the patients according to the measurement time. In the initial period of the study, patients in web-based and standard education groups were found to be homogeneous in terms of disease activity and there was no statistically significant difference between the groups ($p > .05$). It was determined that the disease activity of the patients in both groups decreased during the following measurement times, that more patients entered remission, and that none of the patients had severe disease during the study. Moreover, there was no difference between the education groups in terms of disease activity ($p > .05$).

Table 2 Distribution of Disease Activity of IBD by Time of Measurement

Time	Type of Education	Web Based Education		Standard Education		χ^2	p
		n	%	n	%		
<u>Disease Activity of UC</u>							
<u>Start</u>							
	Remission	5	31.3	4	25.0	0.155	1.000*
	Mild Disease	5	31.3	8	50.0		
	Severe Disease	6	37.4	4	25.0		
	Very Severe Disease	-	-	-	-		
<u>2nd Week</u>							
	Remission	5	31.3	6	37.4	0.182	.913
	Mild Disease	6	37.4	5	31.3		
	Severe Disease	4	25.0	4	25.0		
	Very Severe Disease	1	6.3	1	6.3		
<u>4th Week</u>							
	Remission	8	50.0	8	50.0	0.000	1.000*
	Mild Disease	4	25.0	5	31.3		
	Severe Disease	4	25.0	3	18.7		
	Very Severe Disease	-	-	-	-		
<u>8th Week</u>							
	Remission	8	50.0	10	62.4	-0.508	.722*
	Mild Disease	6	37.5	4	25.0		
	Severe Disease	2	12.5	1	6.3		

Very Severe Disease	-	-	1	6.3		
Disease Activity of CD						
<u>Start</u>						
Remission	5	35.6	9	64.3	2.286	.257*
Mild Disease	8	57.1	4	28.6		
Severe Disease	1	7.1	1	7.1		
Very Severe Disease	-	-	-	-		
<u>2nd Week</u>						
Remission	7	50.0	10	71.4	1.348	.440*
Mild Disease	5	35.7	3	21.5		
Severe Disease	2	14.3	1	7.1		
Very Severe Disease	-	-	-	-		
<u>4th Week</u>						
Remission	7	50.0	10	71.4	1.348	.440*
Mild Disease	5	35.7	2	14.3		
Severe Disease	2	14.3	2	14.3		
Very Severe Disease	-	-	-	-		
<u>8th Week</u>						
Remission	5	35.7	10	71.4	3.590	.128*
Mild Disease	7	50.0	3	21.5		
Severe Disease	2	14.3	1	7.1		
Very Severe Disease	-	-	-	-		

* Fisher Exact Test

Data Related to GIS Symptoms Experienced by The Patients

When the distribution of patients' major GIS symptoms was examined at the beginning of the study, it was seen that initial diarrhea, abdominal pain and faecal blood symptom measurements of the patients in web-based and standard education groups were homogenous, and that there was no statistically significant difference between the groups ($p > .05$). When the distribution of these symptoms at later measurements was examined, it was found that diarrhea symptom was experienced more in the web-based education group during the study, whereas the rate of diarrhea decreased in the standard education group. Abdominal pain symptom was less commonly seen during the study in both education groups; however, the distribution of faecal blood symptom was similar and less common during the study in both education groups (Table 3).

Table 3 Distribution of Diarrhea, Abdominal Pain and Faecal Blood Symptom According to Measurement Time

Majör GIS Symptoms		Web Based Education		Standard Education		χ^2	p
		n	%	n	%		
DIARRHEA SYMPTOM							
Start	No Diarrhea	10	33.4	7	23.3	3.411	.182
	1-5 sever	16	53.3	13	43.3		
	6-10 sever	4	13.3	10	33.4		
2nd Week	No Diarrhea	7	23.3	7	23.3	1.804	.406
	1-5 sever	19	63.4	15	50.0		
	6-10 sever	4	13.3	8	26.7		
4th Week	No Diarrhea	7	23.3	10	33.3	8.216	.007*
	1-5 sever	22	73.4	12	40.0		
	6-10 sever	1	3.3	8	26.7		
8th Week	No Diarrhea	8	26.7	12	40.0	1.339	.381*

	1-5 sever	20	66.7	14	46.7		
	6-10 sever	2	6.6	4	13.3		
ABDOMINAL PAIN SYMPTOM							
Start	No Abd. Pain	9	30.0	11	36.7	2.819	.244
	1-5 sever	17	56.7	11	36.7		
	6-10 sever	4	13.3	8	26.6		
2nd Week	No Abd. Pain	8	26.6	11	36.7	1.098	.578
	1-5 sever	17	56.7	13	43.3		
	6-10 sever	5	16.7	6	20.0		
4th Week	No Abd. Pain	12	40.0	8	26.7	1.200	.412*
	1-5 sever	15	50.0	18	60.0		
	6-10 sever	3	10.0	4	13.3		
8th Week	No Abd. Pain	13	43.3	14	46.7	0.067	1.000*
	1-5 sever	16	53.4	13	43.3		
	6-10 sever	1	3.3	3	10.0		
FEACAL BLOOD SYMPTOM							
Start	No Blood	20	66.7	21	70.0	0.077	1.000*
	1-5 sever	6	20.0	4	13.3		
	6-10 sever	4	13.3	5	16.7		
2nd Week	No Blood	18	60.0	20	66.7	0.287	.789*
	1-5 sever	8	26.7	8	26.7		
	6-10 sever	4	13.3	2	6.6		
4th Week	No Blood	20	66.7	22	73.4	0.317	.779*
	1-5 sever	8	26.7	6	20.0		
	6-10 sever	2	6.6	2	6.6		
8th Week	No Blood	20	66.7	22	73.4	0.317	.779*
	1-5 sever	10	33.3	6	20.0		
	6-10 sever	-	-	2	6.6		

* Fisher Exact Test

It was found that there was a significant difference in terms of severity averages of diarrhea, abdominal pain and faecal blood symptoms of patients in both education groups with regard to time interaction ($p < .05$), however, there was no significant difference in terms of group-time interaction ($p > .05$). There was no difference between the web-based and standard education groups in terms of getting patients' diarrhea, abdominal pain and faecal blood complaints under control, however the standard education group was found to show a higher change in terms of symptom severity averages between the 1st and 8th weeks (Table 4).

Table 4 Comparison of Average Blood Symptom Severity of Diarrhea, Abdominal Pain and Faecal Blood According to Measurement Time

Major GIS Symptoms	Web Based Education	Standard Education	t	p
	$\bar{X} \pm SD$	$\bar{X} \pm SD$		
DIARRHEA SYMPTOM				
Start	2.53 ± 2.30	3.93 ± 3.33	1.894	.064
2nd Week	2.43 ± 2.16	3.36 ± 2.85	1.427	.159
4th Week	2.20 ± 1.82	3.13 ± 2.87	1.501	.140
8th Week	2.20 ± 2.04	2.36 ± 2.44	0.287	.775
t, p	t = 0.854 p = .400	t = 3.065 p = .005**		
Change %	13.04%	39.94%		

Time ^a	F = 5.960	p = .004**		
Group x Time	F = 2.435	p = .096		
ABDOMINAL PAIN SYMPTOM				
Start	2.60 ± 2.67	3.33 ± 3.47	0.916	.364
2nd Week	2.60 ± 2.85	2.66 ± 2.75	0.092	.927
4th Week	2.13 ± 2.54	2.76 ± 2.62	0.950	.346
8th Week	1.80 ± 2.04	1.93 ± 2.39	0.232	.817
t, p	t = 2.449 p = .021*	t = 2.341 p = .026*		
Change %	30.76%	42.04%		
Time ^a	F = 6.991	p = .000**		
Group x Time	F = 0.953	p = .416		
FEACAL BLOOD SYMPTOM				
Start	1.83 ± 3.06	1.63 ± 3.14	-0.249	.804
2nd Week	1.83 ± 2.61	1.36 ± 2.47	-0.711	.480
4th Week	1.60 ± 2.49	1.00 ± 1.96	-1.034	.306
8th Week	1.16 ± 1.76	0.63 ± 1.54	-1.247	.217
t, p	t = 1.904 p = .067	t = 1.750 p = .091		
Change %	36.61%	61.34%		
Time ^a	F = 4.928	p = .003**		
Group x Time	F = 0.277	p = .842		

* p: <.05

t: Two paired t test (Start & 8th week)

** p: <.001

t: Independent t test^a: Analysis of variance in repeated measures

In addition to these three major GIS symptoms, it was found that there was a significant difference between the groups in terms of severity averages of faecal mucus, tenesmus, rectal sensitivity, nausea and decreased appetite symptoms with regard to time interaction; however, there was no statistically significant difference in terms of group-time interaction. In addition, standard education group was found to have a higher rate of change in symptoms, excluding rectal sensitivity, compared to the web-based education group. It was determined that the change in the severity average of only rectal sensitivity symptom was higher in the web-based education group.

Evaluation of Patients' QOL

Patients' average IBDQ scores according to measurement times are presented in Table 5. There was no statistically significant difference between the web-based and standard education groups at the beginning of the study in terms of the average QOL score ($p > .05$).

Table 5 Comparison of IBD QOL Subscales and Total Point Average by Measurement Times

IBD QOL	Web Based Education	Standard Education	t	p
	$\bar{X} \pm SD$	$\bar{X} \pm SD$		
Bowel Symptoms Subscale				
Start	4.60 ± 1.22	4.49 ± 0.96	-0.387	.700
2nd Week	4.59 ± 1.14	4.61 ± 0.96	0.049	.961
4th Week	4.76 ± 1.06	4.72 ± 0.98	-0.176	.861
8th Week	4.83 ± 0.94	4.79 ± 1.07	-0.153	.879
t, p	t = -1.498 p = .145	t = -1.600 p = .121		
Systemic Symptoms Subscale				
Start	4.72 ± 1.24	4.71 ± 1.21	-0.042	.967
2nd Week	4.83 ± 1.20	4.60 ± 1.14	-0.766	.447

4th Week	5.09 ± 1.31	4.66 ± 1.20	-1.311	.195
8th Week	5.04 ± 1.18	4.98 ± 1.35	-0.183	.856
t, p	t = -2.089 p = .046*	t = -1.330 p = .194		
Emotional Symptoms Subscale				
Start	4.75 ± 1.32	4.68 ± 1.16	-0.224	.823
2nd Week	4.65 ± 1.09	4.44 ± 1.11	-0.750	.456
4th Week	4.88 ± 1.16	4.55 ± 1.30	-1.006	.318
8th Week	4.87 ± 1.03	4.71 ± 1.31	-0.537	.593
t, p	t = -0.855 p = .400	t = -0.140 p = .889		
Social Function Subscale				
Start	4.63 ± 1.41	4.78 ± 1.30	0.418	.677
2nd Week	4.50 ± 1.25	4.74 ± 1.23	0.725	.471
4th Week	4.77 ± 1.32	4.79 ± 1.27	0.060	.953
8th Week	4.88 ± 1.33	5.24 ± 1.35	1.015	.314
t, p	t = -1.698 p = .100	t = -2.011 p = .054		
Total Point of Scale				
Start	149.90 ± 38.76	148.60 ± 31.85	-0.142	.888
2nd Week	148.53 ± 34.14	146.10 ± 27.72	-0.303	.763
4th Week	155.56 ± 34.84	149.20 ± 31.66	-0.741	.462
8th Week	156.53 ± 30.97	155.63 ± 34.30	-0.107	.915
t, p	t = -1.642 p = .111	t = -1.171 p = .251		
Change %	-4.42%	-4.73%		
Time ^a	F = 4.268 p = .019*			
	Group x Time F = 0.452 p = .620			

* p: <.05

t: Two paired t test (Start & 8th week)

t: Independent t test

^a: Analysis of variance in repeated measures

The average systemic symptoms sub-dimension score of the patients in the web-based education group was 4.72±1.24 at the beginning, increased gradually throughout the study, and showed a slight improvement at 8th week by 5.04±1.18. In terms of average systemic symptoms sub-dimension scores of the patients in the web-based education group, there was a statistically significant intra-group difference between the beginning and end of the study (t= -2.089; p<.05). There was no statistically significant difference found between the groups in terms of total IBDQ score averages of the patients (p>.05).

It was found that according to the measurement times, there was a significant difference between the average QOL scores of the patients in web-based and standard education groups in terms of time interaction (F=4.268; p<.05), whereas there was no statistically significant difference in terms of group-time interaction (F=0.452; p>.05). In addition, there was no statistically significant difference found between the beginning and end of the study in terms of QOL in both education groups (t_{web}= -1.642; t_{standart}= -1.211; p>.05).

4. DISCUSSION

Examination of Data Related to Disease Activity

Disease activity affects the severity of symptoms experienced. Clinically, disease activity is classified into three groups, mild-moderate disease, moderate-severe disease and severe disease. Bloody, inflamed and watery stool is seen when the disease activity becomes severe (Demirbulat 2013; Truelove, Witts, 1995; Harvey, Bradshaw, 1980). In a study which investigated the GIS symptoms experienced by IBD patients in the last three months, it has been seen that the correlation between abdominal pain, diarrhea and faecal blood symptoms and disease activity was significant and that diarrhea was the most common symptom in active patients and patients in remission (Singh, Blanchard, Walker, et al., 2011). In a qualitative study conducted, it has been also stated that the symptoms which exacerbated disease activities were faecal blood, diarrhea and abdominal pain symptoms (Waljee, Joyce, Wren,

Khan, Higgins, 2009). The active UC bleeding is assuredly accompanied by visible blood in the stool. In case of the increased disease severity, the mucosa bleeds readily. Systemic symptoms such as fever, weight loss, sweating, loss of appetite, nausea and vomiting may also accompany in case of a disease with moderate or severe activity (Demirbulat, 2013; Shannahan, 2002). Contrary to the literature, in our study, the rate of patients in remission was lower among all the patients with UC; however, the rate of patients in remission was much higher among the patients with CD. Having knowledge and self-management of IBD can shorten the duration of inflammation, reduce the severity of the disease and prolong the remission period. In this study, the patients' knowledge about the disease was improved and the patients gained the ability to identify the symptoms of exacerbation in case of disease progression and the situations requiring an application to a health institution. Thus, it was seen that patients' disease activity decreased and the rate of the patients in remission increased at the end of the study.

Examination of Data Related to GIS Symptoms of Patients

The most commonly expressed major GIS symptoms that are experienced by IBD patients are diarrhea, abdominal pain, rectal bleeding, nausea, vomiting, and tenesmus. Patients have described these symptoms as symptoms that have worsened their disease activities (Demirbulat, 2013; Waljee, Joyce, Wren, Khan, Higgins, 2009).

One of the most important indicators of the disease activity and severity is diarrhea. In studies conducted, it has been reported that diarrhea was seen in 66-93% of the patients (Lennard-Jones, Shivananda, 1997; Riegler, Tartaglione, Carratú, et al., 2000), that patients had to go to the toilet once in every thirty minutes as the disease progressed, that this obliged them to go to a hospital, and that they understood that the disease exacerbated by the urinary frequency (Peyrin-Biroulet, Loftus, Colombel, Sandborn, 2011; Waljee, Joyce, Wren, Khan, Higgins, 2009; Aghazadeh, Zali, Bahari, et al., 2005; Farrell, McCarthy, Savage, 2016). In a study, it has been reported that 79.6% of the UC patients and 51.2% of the CD patients had diarrhea (Demirbulat, 2013). These findings are similar to our study findings. Moreover, in both groups, diarrhea was the most commonly reported symptom in more than half of the patients included in the study. It was determined that the time is effective in getting diarrhea symptom under control, but there was no difference between the web-based and standard education groups according to the education type.

Abdominal pain is another common problem in IBD patients. It is the first symptom that indicates the disease progress and mostly leads to the diagnosis. It has been reported that abdominal pain was experienced in both remission period and disease period, without any association with disease activity, and that 20-70% of patients, even in the remission period, had abdominal pain (Lennard-Jones, Shivananda, 1997; Aghazadeh, Zali, Bahari, et al., 2005; O'Connor, Bager, Duncan, Gaarenstrom, 2013). In the study conducted by Demirbulat, 76.7% of UC patients and 97.7% of CD patients were found to have abdominal pain (Demirbulat, 2013). These findings are similar to our study findings, and also the incidence of abdominal pain decreased in the both groups during the study.

It was found that there was a significant difference between the average severity of abdominal pain of the patients in web-based and standard education groups in terms of time interaction ($F=6.991$; $p=.000$), whereas there was no statistically significant difference in terms of group-time interaction ($F=0.953$; $p>.05$). These findings show that both education programs are effective in getting abdominal pain symptom under control. Therefore, it is important to provide education, no matter which program, for the management of this symptom.

Another important symptom that indicates the disease exacerbation is the faecal blood which greatly increases the patients' concerns and affects their QOL. In some studies, the most common complaint was reported as faecal blood symptom (Demirbulat, 2013; Waljee, Joyce, Wren, Khan, Higgins, 2009; Lennard-Jones, Shivananda, 1997). Contrary to the literature, faecal blood symptom was not seen in the large majority of the patients included in our study since most of the patients in both education groups were in remission.

It was determined that there was a significant difference in the faecal blood severity averages of the patients in both education groups in terms of time interaction; however, there was no statistically significant difference found in terms of group-time interaction.

Besides the major GIS symptoms, when the severity averages of faecal mucus, tenesmus, rectal sensitivity, nausea and decreased appetite symptoms which affect the daily lives of patients, increase stress and cause embarrassment were examined, there was a significant difference found between the education groups in terms of time interaction, whereas there was no statistically significant difference found in terms of group-time interaction. These results show that there is no difference between web-based and standard education in getting these patient symptoms under control. Considering the significant decrease in severity averages, both education methods are thought to be effective for patients.

Examination of QOL of Patients

Compared to the studies conducted in Sweden (188.5 ± 28.0), Korea (174.1 ± 33.3) and Greece (178.4 ± 35.3) (Hjortswang, Jarnerot, Curman, et al, 2003; Kim, Cho, Yoo, et al, 1999; Pallis, Vlachonikolis, Mouzas, 2002), the average QOL scores of the patients in web-based and standard education groups who were included in this study were found to be lower than those of the patients in other countries. There was no statistically significant difference determined between the groups in terms of total IBDQ total score and all sub-dimension averages at all measurements of the study. The QOL of the patients increased gradually in both groups according to the measurement times, whereas their QOL was found to be at a moderate level at the end of the study.

In a study conducted with IBD patients who were treated and monitored on the web page, there was no significant difference observed between the beginning and end of the study in terms of patients' QOL score averages (Waters, Jensen, Fedorak, 2005). In Pedersen's study, the QOL of CD patients monitored on the web was at the same level at the beginning and end of the study. However, it has been observed that the disease knowledge of the patients who were included in the e-learning program on a web-based setting significantly increased (Pedersen, Elkjaer, Duricova, et al, 2012). Our study results are consistent with the literature findings. The average QOL scores of the patients in the web-based education group were determined to be higher. Considering the fact that the QOL of patients increased over time, it is thought that providing an education to patients is important in increasing the QOL.

In a web-based initiative called "continuous care" which was developed by Elkjaer et al., the QOL of IBD patients were assessed. It has been found that there was a significant improvement in the QOL of Danish patients in the web-based follow-up group compared to those who were monitored in the polyclinic as a standard, whereas there was no significant difference in the Irish web group (Elkjaer, Shuhaibar, Burish, et al., 2010). In a study in which telemedicine practices and standard care have been compared, the QOL of the patients who received telehealth interventions was significantly higher than that of the patients in the standard care group (190.8 ± 24.2 and 171.6 ± 30.1). It has been seen that the difference between the telehealth and standard care groups in terms of the QOL scores was significant during the 12 months study period, and that there was an improvement in the QOL of the patients over time (Cross, Cheevers, Rustgi, Langenberg, Finkelstein, 2012). This result showed consistency with the time interaction in our study and the QOL of the patients were found to improve over time.

In a meta-analysis that has examined 17 studies, it has been concluded that e-health technologies provided an improvement in disease recurrence, disease activity, QOL, disease knowledge and cost-effective health care and facilitated the remote management of the disease compared to standard polyclinic examinations (Jackson, Gray, Knowles, Cruz, 2016). In a meta-analysis in which six randomized controlled studies, it has been found that remote management of IBD using a web-based support reduced the clinical visits, however, it did not significantly improve patients' QOL, recurrence rates, and hospitalization rates (Huang, Reich, Fedorak, 2014). Contrary to the literature, in our study, it is thought that web-based education does not differ from the standard education, but that web-based education can be at least as efficient and effective as standard education in disease knowledge and in providing cost-effective health care.

Guidelines and different research results have focused on the support of direct access to a multidisciplinary team or other sources (telephone, electronic tools, written materials, etc.) for the repetition of patient education. It has been suggested that there is a lot of information about the disease on the internet. However, there are some doubts about the reliability and accuracy of the information in these sources and therefore individualized education is recommended. In studies conducted on patient education, it has been found that the level of knowledge of the participants increased slightly, but this hasn't a significant effect on QOL (O'Connor, Bager, Duncan, Gaarenstrom, 2013; Waters, Jensen, Fedorak, 2005; Promislow, Walker, Taheri, Bernstein, 2010). Similarly, in our study, it was seen that e-health technologies are beneficial in reaching the correct information in any time and any place and in communicating with the education nurse in a short time when needed.

5. CONCLUSION

Patient education is a very important factor in the management of chronic diseases. According to the results of this study in which the effect of the structured patient education program (IBDPEP) on disease activity, symptom management and QOL, the web-based IBD education program is not different or better than the standard education program in terms of the impact on disease activity, symptom management and QOL. No matter which type of education is given, providing a structured and individualized web-based or standard education program based on the patient needs, preferences and the suitability of the education environment is effective and important. However, for the achievement of the program in a long-term period, it should focus on the patient needs, be actively managed by a nurse and provide an online consultation allowing the patient to ask directly. If a patient knows that he/she is not

alone when receiving a education and that there is a health professional to consult in any time, the impact obtained during standard education can be achieved more quickly and cost-effectively in web-based education programs, as well.

According to these results, these are recommended to

- Provide a structured and individualized education through flexible and accessible, innovative education programs to the patients and their families, considering their needs, preferences and coping skills, and ensure the continuity of this education outside the hospital,
- Educate and train nurses who are acknowledged experts on IBD in order to guide patients, their families, and other health professionals and to extend IBD nursing.

Author's contribution

Conceptualization: BNOU, YY. Methodology: BNOU, YY, FSA, BU. Formal analysis: BNOU. Funding acquisition: BNOU. Writing - original draft: BNOU, YY. Writing - review and editing: BNOU, YY, FSA, BU. Approval of final manuscript: BNOU, YY, FSA, BU.

Conflict of Interest

The authors declare no conflict of interest and financial supports

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REFERENCE

1. Aghazadeh R, Zali MR, Bahari A, et al. Inflammatory bowel disease in Iran: a review of 457 cases. *J Gastroenterol Hepatol.* 2005;20:1691–95. PMID: 16246187
2. Akçura C, Akpınar H, Keskinoglu P. İnflamatuvar bağırsak hastalarında yaşam kalitesi değerlendirme anketinin Türk toplumu için geçerlilik ve güvenilirliğinin değerlendirilmesi. In: 30. Ulusal Gastroenteroloji Haftası; November 2013; Antalya, Turkey.(Presentation In Turkish).
3. Avdal EÜ, Kızılcı S, Demirel N. The effects of web-based diabetes education on diabetes care results: A randomized control study. *Computers Informatics Nursing.* 2011;29(2):101-6. PMID: 21099675
4. Bennett GG, Herring S, Puleo E, et al. Web-based weight loss in primary care: A randomized controlled trial. *Obesity.* 2010;18(2):308-13.PMC3710670
5. Cosnes J, Beaugerie L, Carbonnel F. Smoking cessation and the course of Crohn's disease; An intervention study. *Gastroenterology.* 2001;120:1093-9. PMID: 11266373
6. Cross RK, Cheevers N, Rustgi A, Langenberg P, Finkelstein J. Randomized, controlled trial of home telemanagement in patients with ulcerative colitis (UC HAT). *Inflamm Bowel Dis* 2012;18:1018–25. PMID: 21688350
7. Demir Y, Gözüm S. New trends in health education; web-based health education. *Journal of Dokuz Eylul University Nursing School.* 2011;4(4):196-203.(article in Turkish with an abstract in English)http://acikerisim.deu.edu.tr/xmlui/handle/12345/4603
8. Demirbulat A. The demographic, clinical and laboratory features of ulcerative colitis and crohn disease and correlation of the findings with disease activity. PhD Thesis, Adnan Menderes University, Turkey, 2013.
9. Elkjaer M, Shuhaibar M, Burish J, et al. E-health empowers patients with ulcerative colitis: A randomized controlled trial of the web-guided "constant-care" approach. *Gut.* 2010;59:1652-61. PMID: 21071584
10. Farrell D, McCarthy G, Savage E. Self-reported symptom burden in individuals with inflammatory bowel disease. *J Crohns Colitis.* 2016;315–22.PMC4957479
11. Frolkis A, Dieleman LA, Barkema HW, et al. Environment and the inflammatory bowel disease. *Can J Gastroenterol* 2013;27(3):18-24. PMC3732155
12. Guyatt G, Mitchell A, Irvine EJ, et al. A new measure of health status for clinical trials in inflammatory bowel disease. *Gastroenterology.* 1989;96:804-810. PMID: 2644154
13. Hanauer SB. Inflammatory bowel disease: Epidemiology, pathogenesis, and therapeutic opportunities. *Inflamm Bowel Dis.* 2006;12(1):3–9. PMID: 16378007
14. Harvey RF, Bradshaw JM. A simple index of Crohn's disease activity. *Lancet.* 1980;1:514. PMID: 6102236
15. Heinrich E, Nooijer J, Schaper NC, et al. Evaluation of the web-based Diabetes Interactive Education Programme

- (DIEP) for patients with type 2 diabetes. *Patient Educ Couns*. 2012;86:172-78. PMID: 21616626
16. Hjortswang H, Jarnerot G, Curman B, et al. The influence of demographic and disease-related factors on health-related quality of life in patients with ulcerative colitis. *Eur J Gastroenterol Hepatol* 2003;15:1011-20. PMID: 12923375
 17. Huang VW, Reich KM, Fedorak RN. Distance management of inflammatory bowel disease: Systematic review and metaanalysis. *World J Gastroenterol*. 2014;20(3):829-42. PMID: 24574756
 18. Jackson BD, Gray K, Knowles SR, Cruz P. EHealth Technologies in inflammatory bowel disease: A systematic review. *Journal of Crohn's and Colitis*. 2016;1103–21. PMID: 26928960
 19. Kim WH, Cho YS, Yoo HM, et al. Quality of life in Korean patients with inflammatory bowel diseases: ulcerative colitis, Crohn's disease and intestinal Behcet's disease. *Int J Colorectal Dis*. 1999;14:52–57. PMID: 10207731
 20. Lennard-Jones JE, Shivananda S. Clinical uniformity of inflammatory bowel disease a presentation and during the first year of disease in the north and south of Europe. EC-IBD Study Group. *Eur J Gastroenterol Hepatol*. 1997;9(4):353-359. PMID: 9160197
 21. Lichtenstein GR, Hanauer SB, Sandborn WJ. Practice parameters committee of American College of gastroenterology. Management of Crohn's disease in adults. *Am J Gastroenterol*. 2009;104(2):465-83. PMID: 19174807
 22. Lönnfors S, Vermeire S, Greco M, et al. IBD and health-related quality of life – Discovering the true impact. *J Crohns Colitis*. 2014;8:1281-86. PMID: 24662394
 23. Moher D, Schultz KF, Altman G. The CONSORT statement: revised recommendations for improving the quality of reports of parallelgroup randomised trials. *Lancet* 2001;357:1191–1194. PMID: 11323066
 24. Molodecky NA, Soon IS, Rabi DM, et al. Increasing incidence and prevalence of the inflammatory bowel diseases with time based on systematic review. *Gastroenterol*. 2012;142:46–54. PMID: 22001864
 25. Mowat C, Cole A, Windsor A, et al. Guidelines for the management of inflammatory bowel disease in adults. *Gut*. 2011;60(5):571-607. PMID: 21464096
 26. O'Connor M, Bager P, Duncan J, Gaarenstrom J. N-ECCO consensus statements on the European nursing roles in caring for patients with Crohn's disease or ulcerative colitis. *J Crohns Colitis*. 2013;7:744-64. PMID: 23831217
 27. Ozgursoy Uran BN, Unsal Avdal E, Mete A, Akbas D. The effect of inflammatory bowel disease in the elderly population. *Medical Science*, 2017, 21(86), 173-179
 28. Pallis AG, Vlachonikolis IG, Mouzas IA. Assessing health-related quality of life in patients with inflammatory bowel disease in Crete, Greece. *BMC Gastroenterol*. 2002;2:1. PMID: 11866863
 29. Pedersen N, Elkjaer M, Duricova D, et al. eHealth: individualisation of infliximab treatment and disease course via a self-managed web-based solution in Crohn's disease. *Aliment Pharmacol Ther*. 2012;36:840-49. <https://doi.org/10.1111/apt.12043>
 30. Peyrin-Biroulet L, Loftus EV Jr, Colombel JF, Sandborn WJ. Long-term complications. extraintestinal manifestations. and mortality in adult Crohn's disease in population-based cohorts. *Inflamm Bowel Dis*. 2011;17(1):471-78. PMID: 20725943
 31. Promislow S, Walker JR, Taheri M, Bernstein CN. How well does the Internet answer patients' questions about inflammatory bowel disease? *Can J Gastroenterol*. 2010;24:671–77. PMID: 21157582
 32. Rezailashkajani M, Roshandel D, Ansari S, Zali MR. A web-based patient education system and self-help group in Persian language for inflammatory bowel disease patients. *Int J Med Inform*. 2008;77:122–28. PMID: 17208516
 33. Riegler G, Tartaglione MT, Carratú R, et al. Age-Related Clinical Severity at Diagnosis in 1705 Patients with Ulcerative Colitis. *Dig Dis Sci*. 2000;45(3):462-65. PMID: 10749318
 34. Shannahan F. Crohn's disease. *Lancet* 2002; 359: 62-69. PMID: 11809204
 35. Singh S, Blanchard A, Walker JR, et al. Common symptoms and stressors among individuals with inflammatory bowel disease. *J Clin Gastroenterol Hepatol*. 2011;9:769-75. PMID: 21645640
 36. Truelove SC, Witts LJ. Cortisone in ulcerative colitis:Final report on a therapeutic trial.*BMJ*.1995;2:1041-48. PMID: 13260656
 37. van der Marel S, Duijvestein M, Hardwick JC,et al. Quality of Web-based information on inflammatory bowel diseases. *Inflamm Bowel Dis* 2009;15(12):1891–1896. PMID: 19462423
 38. Waljee AK, Joyce JC, Wren PA, Khan TM, Higgins PD. Patient reported symptoms during an ulcerative colitis flare: a Qualitative Focus Group Study. *Eur J Gastroenterol Hepatol* 2009;21(5):558–64. PMID: 19194304
 39. Waters BM, Jensen L, Fedorak RN. Effects of formal education for patients with inflammatory bowel disease: A randomized controlled trial. *Can J Gastroenterol*. 2005;19(4):235-44. PMID: 15861266