

Evaluating the Perception of Mycosis Fungoides Patients About Their Disease Before and After Educating Them

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ABSTRACT Introduction: Patient-held beliefs are important for disease management and few studies have evaluated illness perception of Mycosis Fungoides (MF) patients.

Objectives: Here, we aimed to determine the effect of educating MF patients on their perception of their disease.

Methods: Patients with diagnosed MF were asked to fill the Illness Perception Questionnaire-Revised (IPQ-R) once before education and once 3 months later.

Results: Fifty-five patients, 41 men and 14 women, with a mean age of 45.5 ± 13.9 years were enrolled. Regarding the main etiologic factor, most patients cited anxiety (91%). After education, the most significant changed belief on disease etiology was immune system dysfunction and the change was twenty-six percent which was observed more in patients with higher educational levels, shorter disease duration, and lower MF stages. Regarding the most prevalent clinical manifestations, most patients mentioned erythema (86%). After education, the greatest change in symptom perception was related to lymphadenopathy (32%) which was significantly associated with less disease duration and those treated with phototherapy. Before education, the mean perception score about the disease chronicity was 23.67 ± 3.549 that increased to 27.71 ± 1.66 ($P < 0.001$). This change was more observed in men ($P = 0.03$), those with less disease duration, and those treated with phototherapy.

Conclusions: Generally, MF patients hold favorable perspectives about their disease and educating them positively improves their illness perception. Patients with higher educational levels and lower stages of the disease showed more significant changes in various aspects of illness perception. Hence, early education is recommended in patients with lower educational levels.

Introduction

Mycosis Fungoides (MF) is the most common type of cutaneous T-cell lymphomas (CTCL). The annual incidence of MF is estimated at approximately 6:1,000,000 [1-3]. The common age of onset is 55-60 years, and the prevalence of the disease in men is reported to be 2 times higher than in women [2-4].

The most common clinical manifestations of MF are slowly progressive patches and plaques on the trunk that might be scaly or pruritic [5,6].

Due to the long course of the disease, patients with MF will experience annoying symptoms such as pain and itch for a considerable period of time, and their skin lesions may lead to social anxiety, embarrassment, and isolation [7]. Also, currently available treatments do not cause long-lasting remission of the disease which can have financial, emotional, and functional burdens for patients [8].

The concept of illness perception is based on Leventhal self-regulatory model and deals with the relationship between the nature of the disease, the patient concern about the disease, coping processes, and health outcomes [9,10]. Patient-held beliefs are very important for the clinical management of their disease. Also, it has been proved that acquiring more knowledge about the disease is associated with a better understanding of the illness and more personal and treatment control [11].

In previous studies on MF, patients illness perception was assessed in a one-time examination or in two-time assessments without any educational intervention regarding the disease between the two evaluations. Hence, the data in this area is lacking.

Objectives

Since MF patient interpretation and perception can affect different aspects of their lives, this study aimed to determine the effect of educating MF patients on their perception of their disease.

Methods

Participants, Questionnaire, and Data Collection

An analytical, cross-sectional study was conducted in Razi dermatology hospital, Tehran, Iran from March 2020 to July 2020. The study was approved by the ethical committee of Tehran University of Medical Sciences (IR.TUMS.

MEDICINE.REC.1399.266). Information about the study was given to all participants and each participant signed a form of consent for taking part in our study.

Sixty patients with MF diagnosed based on both clinical and histopathological studies aged between 19 and 74 years were enrolled in the study.

A checklist including demographic and clinical characteristics of participants was filled out for each patient. Afterward, the patients were asked to fill the Illness Perception Questionnaire-Revised (IPQ-R) once before educating them on their disease characteristics and once 3 months after the education. The given education included patient-oriented information about MF etiology, prevalence, clinical manifestations, diagnosis, treatment, and the prognosis given in the format of an educational catalog. The educational material was first explained to all patients by a dermatologist and then given to them for further reading. Of 60 participants who completed the IPQ-R questionnaire in the first assessment, 5 did not complete the questionnaire in the second round.

The IPQ-R had been previously translated to the Persian language and its validity and reliability were confirmed [12]. The IPQ-R evaluates patients' perspectives across seven subscales: timeline acute/chronic, timeline-cyclical, consequences, personal control, treatment control, illness coherence, and emotional representations. Moreover, a checklist of clinical symptoms was shown to patients and they were asked to choose the most important factors causing their disease from a checklist of possible etiologic factors (supplementary file 1).

Data Analysis

Statistical analysis was performed by using IBM SPSS Statistics 26. Frequency and percentage were reported for qualitative variables, and mean and standard deviation for quantitative variables. To compare the mean scores between discrete independent variables, independent T-test and one-way Anova test was used. Also, the Pearson correlation coefficient was used to evaluate the correlation between continuous variables. A P of less than 0.05 was considered as significant.

Results

Sociodemographic Characteristics

A total of fifty-five patients, 41 (74.5%) men and 14 (25.5%) women, with the mean age of 45.5 ± 13.9 years (range 19-74) were enrolled in the study. The demographic data are

Table 1. Sociodemographic characteristics of the patients.

Characteristic		
Age, years, mean \pm SD	45.5 \pm 13.9	
Gender, N (%)	male	41 (74.5%)
	female	14 (25.5%)
Marital status, N (%)	single	16 (29.1%)
	married	39 (70.9%)
Education level, N (%)	under high school diploma	20 (36.4%)
	high school diploma and associate degree	14 (25.5%)
	bachelor and masterdegree	17 (30.9%)
	doctorate and more	4 (7.3%)
Duration of the disease, N (%)	less than 2 years	20 (36.4%)
	2-) years	23 (41.81%)
	4-6 years	6 (10.90%)
	6-8 years	4 (7.27%)
	8-10 years	2 (3.63%)
Stage of the disease, N (%)	Stage IA	18 (32.7%)
	Stage IB	14 (25.5%)
	Stage IIA	7 (12.7%)
	Stage IIB	9 (16.4%)
	Stage IIIA	4 (7.3%)
	Stage IVA	3 (5.5%)
Skin lesions, N (%)	patch	23 (41.8%)
	plaque	18 (32.7%)
	cutaneous tumor	10 (18.2%)
	generalized erythema	4 (7.3%)
Palpable lymph nodes, N (%)	no	37 (67.3%)
	yes	18 (32.7%)
Type of treatment, N (%)	phototherapy	39 (70.9%)
	phototherapy with additional treatment	16 (29.1%)

shown in Table 1. Considering the stage of the disease, the most prevalent stages among 55 patients were stage IA in 18 (32.7%) and stage IB in 14 (25.5%), respectively (Table 1).

Beliefs About the Cause of the Disease

Before educating the patients, the most common etiologic factors associated with their disease based on patients beliefs were stress and anxiety (91%), familial worries and problems (82%), and emotional states (76%). While after educating the patients, the most prevalent etiologic factors were stress and anxiety (94%), familial worries (83%), and immune system dysfunction (73%). After educating the patients, the most significant change in the mean score of perception about the disease etiology was related to immune system dysfunction (26%), smoking and drug abuse (20%), and hereditary factors. This change was reported more in patients with higher educational levels, lower stages of the disease, and shorter illness duration.

Beliefs About Illness Coherence

Before training, the achieved score about patients illness coherence was 13.82 ± 3.65 and after the training, this score was 17.80 ± 2.81 (range 5-25). This proves that most patients had an acceptable knowledge about their disease and after the training, their knowledge improved ($P < 0.001$). After educating the patients, the educational level had a positive relationship with illness coherence ($P < 0.001$) and with the changes in patients' beliefs about illness coherence ($P = 0.019$). Also, there was a negative relationship between patients age and their beliefs about illness coherence ($P = 0.004$).

Beliefs About the Symptoms

Before educating the patients, the most common reported symptoms were erythema (86%), pruritus (75%), and scaling (68%). In the second assessment, the first three common symptoms were again erythema (100%), pruritus (92%), and scaling (84%), but they were different from those in

the first assessment regarding their frequency. After instructing the patients about their illness, the greatest change in terms of symptom perception was related to lymphadenopathy (32%), pruritus (17%), and scaling (16%). The change in patients beliefs was more pronounced in patients with shorter disease duration, patients with patches and plaques type lesions, and those receiving phototherapy.

Beliefs About Chronicity and Recurrence

Before informing the patients, the mean perception score about the disease chronicity was 23.67 ± 3.549 ; after educating the patients, this score was 27.71 ± 1.66 (range 6-30). The given scores show that most patients accepted that their disease is a chronic situation and this attitude increased significantly after training ($P < 0.001$). Regarding the disease timeline-cyclical, before and after training, the scores were 13.00 ± 2.40 (range 4-20) and 16.31 ± 1.78 (range 4-20), respectively. This shows that most patients consider their illness as a recurrent situation and this belief increased significantly after the training ($P < 0.001$). Beliefs about the disease chronicity changed significantly after the training in both genders and it was more prominent in men ($P = 0.03$). After educating the patients, as the educational level increased, the awareness about the disease chronicity increased ($P < 0.001$). After the training, the stage of the disease had a positive relationship with beliefs about the chronicity of the disease ($P < 0.001$).

Beliefs About Consequences

Comparing the patients beliefs scores about their disease consequences between the first (18.53 ± 3.681) and the second (19.55 ± 3.66) assessments shows that patients knew

about the negative consequences of their illness and this attitude increased after the training ($P = 0.005$). After the training, the stage of the disease had a positive relationship with beliefs about consequences ($P > 0.001$).

Beliefs About Cure and Control

The achieved score before and after the training was 20.69 ± 3.82 and 23.71 ± 2.85 , respectively ($P < 0.001$) indicating that most of the patients were aware of their role in controlling their disease and this increased significantly after the training. Also, comparing the scores of their beliefs about treatment control before (18.60 ± 3.010) and after (22.45 ± 1.74) the training showed that most patients believed that treatment has an acceptable role in controlling the disease and improving the clinical symptoms ($P < 0.001$). Moreover, the educational level had a positive relationship with the changes in beliefs about treatment control ($P = 0.011$).

Beliefs About Emotional Representation

Before the training, most patients complained about the negative effects of this illness on their emotions (22.35 ± 5.372). After the training, this amount increased significantly (24.00 ± 3.03 ; $P = 0.004$). There was a positive relationship between negative effects on emotions and stages of the disease after the training ($P = 0.047$). Moreover, after educating the patients, as the educational level increased, negative effects on emotions enhanced ($P = 0.025$) (Table 2).

Conclusions

MF is the most common type of CTCL and can influence various aspects of patients lives. The results of our study

Table 2. Perception modalities before and after educating the patients.

	Mean	Number	Standard Deviation	P
Timeline-Acute/Chronic 1	23.67	55	3.549	< 0.001
Timeline-Acute/Chronic 2	27.71	55	1.663	
Consequences 1	18.53	55	3.681	0.005
Consequences 2	19.55	55	3.366	
Personal control 1	20.69	55	3.829	< 0.001
Personal control 2	23.71	55	2.859	
Treatment control 1	18.60	55	3.010	< 0.001
Treatment control 2	22.45	55	1.741	
Illness coherence 1	13.82	55	3.657	< 0.001
Illness coherence 2	17.80	55	2.811	
Timeline-cyclical 1	13.00	55	2.404	< 0.001
Timeline-cyclical 2	16.31	55	1.783	
Emotional representation 1	22.35	55	5.372	0.004
Emotional representation 2	24.00	55	3.031	

1= BEFORE; 2= AFTER.

indicate that MF patients have an acceptable understanding of their disease, its causing factors, and clinical manifestations associated with their disease which significantly increases after training them.

The fact that patients have an acceptable perception of their illness has been confirmed in previous studies on various dermatologic diseases including vitiligo and skin cancers and is consistent with our study [13-15]. A study by Topal et al on 100 vitiligo patients using IPQ suggested that patients had good knowledge about their disease and were highly aware of the etiologic factors [14]. Despite the low prevalence of MF, the patients in our study had a good knowledge about their disease which significantly increased after educating them. The opposite results were observed in a study done by Eder et al that believed patients with CTCL have a poor understanding of their disease. This poor knowledge was attributed to the low prevalence of the disease and the unknown cause of CTCL [8].

Our study showed that educating MF patients cause significant changes in beliefs about different factors such as the etiologic factors, clinical manifestations, disease chronicity and recurrency, emotional impacts, illness consequences, personal control, and treatment control. These changes indicate that educating MF patients help them to have a better knowledge about their illness. Generally, changes in patients perception about the clinical manifestations, consequences, and emotional representations were more notable than other variables after the education.

Regarding the main etiologic factor, the results of our study showed that most patients with MF cited stress and anxiety as the main causing factor for their illness. The same results were also found in Firooz et al study which assessed 80 vitiligo patients using IPQ and observed that a total of 62.5% of patients believed that stress was a major factor in causing their disease [13]. After the education, the greatest change in the knowledge of patients in etiology was observed in patients with higher educational levels, shorter disease duration, and lower stages of MF. This indicates that educating MF patients as early as possible may have a better influence on patients perception of their disease. It is worth mentioning that after the education, patients with lower educational levels did not show significant changes regarding the etiologic factors which highlight the point that more efforts should be made in educating these groups of patients and different means of education rather than a single brochure should be considered for them.

In terms of clinical manifestations, most of our patients mentioned erythema, pruritus, and scaling as the most prevalent clinical manifestations. After instructing the patients about their illness, the greatest change in terms of symptom perception was related to lymphadenopathy meaning that lymphadenopathy might not be noticed by patients if the

physicians do not educate patients about it. After educating them, the greatest change in the amount of knowledge about the MF clinical signs was observed in those with less disease duration, those who manifested patches or plaques and those who were being treated with phototherapy. This finding can be suggestive of the fact that educating those who are only treated with medications does not result in a desirable change in their illness perceptions in comparison to therapies such as phototherapy that requires more visits by the physicians.

Our study shows that MF patients have an acceptable knowledge about the chronic and recurrent nature of their disease that significantly increases after training especially in men, those with less disease duration, and those who were only treated with phototherapy. As seen in Fortune et al that investigated 162 patients with psoriasis and observed that a vast majority of patients believed their disease was more likely to be chronic or recurrent, while only a short number of them considered their condition to be temporary [16].

Regarding the beliefs about the disease negative consequences, after the education, patients had a better understanding of their diseases' negative consequences, especially in those with higher stages of MF.

MF has a severe negative emotional impact on patients that significantly increases after educating them. Although a negative perception about the consequences of illness is not the equivalent of having a psychiatric disorder, it may increase the likelihood of developing the disorder [16]. The greatest change regarding the negative emotional feelings toward the disease was observed in those with less disease duration and those who had lower stages of MF. Since the greatest changes in patients illness perception were observed among patients with less disease duration and lower stages of the disease, it is important to educate patients in the early stages of their illness.

Most of our patients believed that they have an important role in controlling their illness that significantly improved after educating them. The greatest change in this belief was observed in those with higher educational levels. Notably, in Eder et al study, it was observed that patients had limited belief in personal control, but a strong belief in treatment control which was attributed to their sample consisting of patients with long disease duration [8]. In general, MF patients hold favorable perspectives about their disease and educating them positively improves their views about their illness. Also, patients with higher educational levels and lower stages of the disease showed more significant changes in various aspects of illness perception. Hence, early education is recommended in patients with lower educational levels. More research on increasing MF patients understanding of their illness should be done, since correcting patients misconceptions is associated with increased follow-up and improved treatment outcomes.

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