

Evaluation of quality of life in patients with Mycosis fungoides in Isfahan in 2017-2019

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Abstract

Objective Mycosis fungoides (MF) is a condition of the lymphatic tissues that mostly affects the skin (primary cutaneous T cell lymphoma), the most prevalent form of T-cell skin lymphoma. Central lymph node and other organs involvement are very poor prognostic factors that can gradually affect the quality of life of these patients. Therefore, in this study, we aimed to examine the quality of life in patients with MF.

Methods In this descriptive study, a demographic questionnaire including age, gender, duration of MF, stage of the disease, and location of the lesion was completed. All participants were tested for quality of life using the SF36 questionnaire.

Results There was a significant difference between different stages of the disease as well as the duration of the disease with respect to the overall quality of life score and its subscales, so that with increasing stage and duration of the disease, the quality of life decreased ($P < 0.05$). The quality of life was lower in patients with sun-exposed areas than in those with other affected areas ($P < 0.05$).

Conclusion MF disease is correlated with reduced quality of life and the extent of which is inversely related to the duration of the disease as well as the stage of the disease. Additionally, patients with affected areas that are exposed to sunlight have a lower quality of life than those with other affected areas.

Key words

Mycosis fungoides, quality of life, skin lesions, SF-36.

Introduction

Mycosis fungoides (MF) is a condition of the lymphatic tissues that mostly affects the skin (primary cutaneous T cell lymphoma), the most prevalent form of T-cell skin lymphoma (65% of Pctcl), and which occasionally coexists with Sezary syndrome.¹ The prevalence of MF is increasing, which could be due to better

diagnosis or the actual increase in its prevalence. Initially, MF appears as eczematous lesions or patches or flat, round, or tumor lesions with a red surface, which together they do not have the right scale. Although many patients never show any progression of the disease, some may progress from patches and plaques to large plaques or tumors and even erythroderma.^{2,3}

Plaques can be itchy, maybe associated with secondary bacterial infection, and these patients are at high risk for morbidity and low quality of life, even though they are in the early stages of the disease.^{3,4} The progression of the disease in the form of peripheral or central

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lymphadenopathy or other organs involvement can change the prognosis of disease. A percentage of patients who progress to lymph node or other organs involvement eventually present with B symptoms (fever and weight loss). Central lymph node and other organs involvement are very poor prognostic factors that can gradually affect the quality of life of these patients.³

On the other hand, MF is a chronic disease and there are several treatments for it and each of them has its own side effects. Because skin plays an important role in social communication and social acceptance, skin disorders can play an important role in verbal and non-verbal rejection, and because this rejection is emotionally very painful, patients with these skin disorders are out of action to avoid exposing their skin to the public.⁵ They may also be affected by daily personal and social activities, peace of mind, and personal relationships due to their skin condition. On the other hand, the negative view of patients with such skin disorders towards their body leads to low self-esteem, social isolation, occupational and educational injuries, and in general, these people are more sensitive to the behavior of others than themselves.^{6,7} All in all they are emotionally healthy people and all of the above-mentioned factors can lead to severe depression and ultimately reduced quality of life. Another factor that affects the quality of life of these patients is the numerous visits to skin clinics to receive various long-term treatments that require a lot of time and money that can indirectly affect the quality of life.^{6,7}

To the best of our knowledge, a few researches has been conducted on the impact of MF on patients' quality of life. Additionally, there hasn't been any research on how the MF condition affects Iranians' quality of life. Given the side effects of treatment and prognosis of these

patients, no study has been done on the impact of this disease on the quality of life. In this study, we aimed to study the quality of life in patients with MF in Isfahan, Iran.

Methods

The present study is a cross-sectional study that was performed in Isfahan in 2017-2019. The target population of the study was patients with MF who were visited in the dermatology clinic of Al-Zahra Hospital in Isfahan. Inclusion criteria of the study includes being affected with MF, consent to enter the study and living in the city of Isfahan. Exclusion criteria of the study includes other skin diseases, other chronic diseases and dissatisfaction to continue study. A total of 270 patients with MF were selected by an incredibly easy method of sampling.

An informed consent form was completed for all patients participating in the study prior to the initiation of the study. The demographic questionnaire was then completed, including age, gender, duration of MF, stage of the disease, and location of the lesion. All participants were tested for quality of life using the SF36 questionnaire. The Quality of Life Questionnaire (SF36) has 36 questions and consists of eight scales, each of which consists of 2 to 10 articles. The scales of this questionnaire include Physical Functioning, Role Physical, Role Emotional, Vitality, Mental Health, Social Functioning, Bodily Pain, and General Health.

Data were analyzed using SPSS software (version 20). Kolmogrov-Smirnov Z-test was used to investigate the normal distribution of data. Mann-Whitney U test and Independent t-test were used to compare numerical variables between independent subgroups. P-value less than 0.05 was considered significant.

Results

In this study, 270 patients with MF were examined, of which 132 patients (48.9%) were male and 138 patients (51.1%) were female. The mean age in these patients was 59.72±12.77 years. The stages of the disease in which each patient was present during the study were IA (52.2%), IB (31.5%), IIA (1.5%), IIB (2.2%), IIIA (5.9%), IIIB (2.6%), IVA (1.1%), and IVB (3%). The average duration of the disease was 9.03±2.88 years. The average overall score of quality of life was 62.20±7.92 (Table 1).

Table1 Mean of subtypes of quality of life in MF patients.

	Mean	Std. Deviation
Overall	62.2065	7.92625
Physical Functioning	55.2593	22.94797
Role Physical	55.1074	22.51360
Role Emotional	52.8741	20.97597
Vitality	56.8704	23.47224
Mental Health	55.7556	22.72969
Social Functioning	48.4148	19.80045
Bodily Pain	52.9852	22.38510
General Health	58.1667	23.16736

There was no significant difference between the two genders in terms of overall score of quality of life as well as its subscales except for physical role (P>0.05). There was a significant difference between the types of disease stages in terms of overall score of quality of life as well as half of its subscales, so that with increasing disease stage, quality of life decreased (P<0.05). A comparison between the other clinical features and the overall score of quality of life as well as its subscales is shown in Table 2.

Discussion

The results of our study showed that the mean score of quality of life and its subscales are not associated to gender and age. However, the overall quality of life score and most of its subscales decrease significantly as the disease progresses. The overall score of quality of life

Table 2 Quality of life and its subtypes with respect to clinical characteristics.

	Physical Functioning	Physical Role	Emotional Role	Vitality	Mental Health	Social Functioning	Bodily Pain	General Health	Overall
Gender									
Male	57.62±22.77	52.20±22.44	52.14±21.41	58.09±24.24	56.96±24.06	46.06±18.72	50.68±22.15	57.99±22.67	61.62±7.92
Female	52.99±22.96	57.88±22.30	53.57±20.59	55.70±22.74	54.60±21.39	50.65±20.59	55.18±22.46	58.33±23.71	62.76±7.91
P-value	0.10	0.02	0.43	0.34	0.29	0.11	0.11	0.82	0.23
Stage									
IA	57.83±23.15	60.15±21.77	54.52±20.86	59.85±24.06	60.75±21.64	51.11±20.42	54.52±22.89	60.63±23.52	65.80±6.42
IIA	46.25±28.14	42.75±32.45	31.50±7.93	60±19.25	67.25±27.04	53.75±24.48	35.25±16.33	71.25±25.38	57.50±1.68
IIIA	49.43±20.81	51.12 ±23.06	42.93 ±21.07	45.56±23.06	47.87±23.18	40.62±15.29	43.12±16.35	54.12±23.61	53.96±3.71
IV A	58.66±20.30	32±3.60	40±13.07	46.33±23.45	34.66±12.50	29.33±8.08	52.33±25.69	31.66±8.50	47.58±3.40
IB	55.29±22.73	53.56±21.32	54.27±20.46	56.40±21.87	53.08±23.29	48.44±18.82	55.44±22.63	58.44±20.93	61.63±6.40
IIB	52±24.13	48.28±21.73	44.28±6.82	47.85±29.70	41.57±9.41	50.71±23.91	43±22.28	48±25.43	54.48±2.08
IIIB	46.33±25.35	35.83±13.49	56.83±32.48	41±13.02	38±18.23	32.33±10.98	41.50±15.37	34.50±20.81	48.12±4.29
IVB	33.87±10.02	25.75±12.85	48.87±24.71	54.12±26.10	39.75±19.63	30.62±8.19	45.87±19.10	49.75±26.75	46.43±2.75
P-value	0.11	0.00	0.07	0.09	0.001	0.003	0.15	0.01	0.00
Area									
Photoexposed	57.09±19.37	39.81±17.03	43.54±13.57	62.27±24.56	40.72±23.67	38.54±16.86	51.54±24.84	42.18±21.33	54.35±8.75
Non-photoexposed	55.18±23.11	55.75±22.51	53.27±21.15	56.64±23.44	56.39±22.51	48.83±19.83	53.04±22.32	58.84±23.03	62.54±7.73
P-value	0.80	0.01	0.14	0.40	0.01	0.06	0.88	0.01	0.001
Disease Duration									
≤10	55.83±23.56	58.43±21.89	54.49±20.48	59.02±23.24	57.95±22.32	50.47±20.03	52.71±22.45	59.46±23.01	64.18±7.13
>10	53.29±20.76	43.72±20.96	47.31±21.83	49.47±22.90	48.22±22.66	41.36±17.35	53.91±22.31	53.70±23.30	55.43±6.69
P-value	0.49	0.00	0.009	0.007	0.003	0.001	0.69	0.62	0.00

and most of its subscales decrease significantly with increasing duration of the disease. Furthermore, the overall quality of life score and some of its subscales in patients with areas exposed to sunlight from their bodies is significantly lower than those with areas of the body that are not exposed to sunlight.

In a related study, McCaffrey *et al.*⁸ used the Patients Like Me Open Research Exchange to collect preliminary data on the quality of life of 126 patients with MF or Sézary syndrome (SS) subtypes of cutaneous T-cell lymphomas (MF/SS-CTCLs) and a comparator measure of health-related quality of life (Skindex-29). To assess test-retest reliability, the MF/SS-CTCL quality of life was again completed by 66 participants 5 days later. Their results showed that patients with MF have low quality of life. However, inconsistent with our study, they did not investigate the correlations between demographic and clinical variables with quality of life score and its subtypes.

In another study that was carried out by Molloy *et al.*,⁹ the authors assessed quality of life in 186 patients with MF/SS using Skindex-29. Furthermore, they evaluated associations between quality of life and other clinical and demographic variables. Inconsistent with our study, they found that female patients had lower quality of life compared with male patients. However, in line with results of our study, they showed that late-stages patients have lower quality of life compared with other MF patients. The most important difference between our study and their investigation that may in part explain the difference in findings is the type of questionnaire that was used for assessment of quality of life.

In a study by Wright *et al.*¹⁰ quality of life and pruritus were assessed using Skindex-29 and visual analogue scale for itch (VAS) in 175

patients with CTCL. In CTCL, every area of QOL is impacted. Pruritus is a common and inconvenient symptom. In this study, a lower QOL was linked to a more advanced illness stage and more intense pruritus symptoms.

Similar to other chronic and debilitating diseases, MF can cause problems that affect all aspects of a person's life. These patients often experience feelings of failure and frustration due to the conflict with the disease and its treatment planning, and their sense of well-being and social well-being are affected. Many of them report feelings of fear, anger, and guilt associated to the disease and they often do not have enough motivation to take care of themselves and control the disease accurately.¹¹ Chronic complications of MF including reduced life expectancy and mortality impose a heavy economic burden on the individual, the family and society, and affect the quality of life of the individual and the family. Indeed, although skin diseases are not fatal and do not interfere with daily activities, but similar to other diseases, they affect the quality of life of people, especially when the symptoms of the disease appear in exposed areas of the body such as the skin.¹²

In comparison to other lymphoproliferative diseases, in a study Mols and colleagues in 2007, they investigated the QOL of patients with non-Hodgkin lymphoma and indicated that the QOL score of patients were between 73 to 81 which was almost similar to normal population.¹³ This issue was also indicated in other studies.^{14,15} Other studies on patients with Hodgkin lymphoma showed that the QOL of these patients are almost 72 to 76 but is lower than normal population.^{16,17} Based on our study, patients with MF have lower QOL score compared to other lymphoproliferative diseases. Compared with psoriasis, Nazik and colleagues indicated that patients with Psoriasis have lower

QOL compared with normal population and their mean QOL score was 64.9 which is almost similar to patients with MF.¹⁸ Patients with atopic and chronic dermatitis also have lower QOL than normal population and also than patients with lymphoproliferative diseases which could also be due to skin manifestations of the disease.^{19,20} We believe that skin manifestations of MF might play pivotal roles in reducing QOL scores in patients with MF. This issue has not been addressed before.

Conclusion

MF disease is associated with reduced quality of life and the extent of which is inversely related to the duration of the disease as well as the stage of the disease. Additionally, patients with affected areas that are exposed to sunlight have a lower quality of life than those with other affected areas.

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