The Impact of Morphea on Quality of Life Over Time

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Background

Morphea, also known as localized scleroderma, is an inflammatory disorder that has subsequent clinical manifestations of sclerosis and atrophy of the dermis and underlying tissue. Epidemiologically, morphea is a relatively rare disorder with a reported annual incidence of approximately 3 per 100,000 people in the United States between 1960 and 1993 [1]. Morphea can occur at any age though the majority have adult onset of disease. Demographically, females are more susceptible by a female to male ratio of approximately 3:1. The duration of disease activity is typically three to six years, though resulting cosmetic disfigurement or functional impairments are likely to persist even after the transition to inactive disease [2]. There are, however, a minority of patients that develop a recurrence in activity for which there currently are no predictive markers [3]. This uncertainty can lead to patient anxiety even when the disease has progressed to an inactive stage. It has been widely established that dermatologic disease has an adverse effect on quality of life (QoL) of patients[4]. QOL can encompass functional and psychiatric morbidity as well as extend to social aspects of life. For a clinician, a patient's perspective of their future in the context of their values can elucidate which aspects of disease are important [5]. The impact of Morphea on a patient's self-reported health-related quality of life (HRQOL) over time is not well described in medical literature.

Objective

- To determine the impact of specific clinical and demographic variables on HRQOL via a longitudinal survey of the Morphea in Adults and Children (MAC) cohort. As a secondary aim, the assessment of physician measures was compared to HRQOL to elucidate which aspects of disease are important to patients. We hypothesize that morphea has a significant impact on QoL at baseline, but this effect is mitigated with time and treatment .

Methods

Patients: Adult patients of the MAC cohort with ≥ 2 visits with a recorded HRQOL measure were studied. A total of 110 patients with 307 visits were included in the analyses. In order to capture physician assessment of disease, Physician Global Assessment of disease (PGA), *Modified Rodnan Skin Score* (*MRSS*) and Localized Scleroderma Skin Severity Index (LOSSI) with its damage correlate LOSDI were employed. Self-reported HRQOL was examined via three previously validated questionnaires.

Questionnaires:

DLQI: Each included patient had at least 2 Dermatology Life Quality Indexes (DLQI). The DLQI is a 10 question survey which measures six subscales (symptoms and feelings, daily activities, leisure, treatment, personal relationships, work and school) over the course of the week prior to survey administration. DLQI scores range from 0 to 30, with higher scores indicating poorer QOL.

Skindex-29+3: Skin specific QoL was also measured using the Skindex-29 when available. The survey contains 29 questions used to calculate three subscales: emotions, symptoms, and functioning. A morphea-specific subscale was added to include measures for anxiety that the condition would spread to internal organs, or if that the rarity of the disease creates feelings of isolation. The Skindex is score from 0 to 100, with higher scores indicating poorer QOL.

SF-36: General QOL was also measure using the Short Form-36 (SF-36) when available. The SF-36 is a 36-item questionnaire that analyses 8 subscales: physical functioning, role-physical, general health, bodily pain, mental health, vitality, role-emotional, and social functioning. These are used to calculate 2 summary scores, Physical Component Score [PCS] and Mental Component Score [MCS]. Scores are calibrate so that 50 is the norm, which allows for comparison with other medical conditions as well as the general population. Higher scores indicate a better QOL.

Variables of interest:

Baseline-Demographics, subtype of disease, co-morbidity
Longitudinal- symptoms, treatment, disease severity and activity

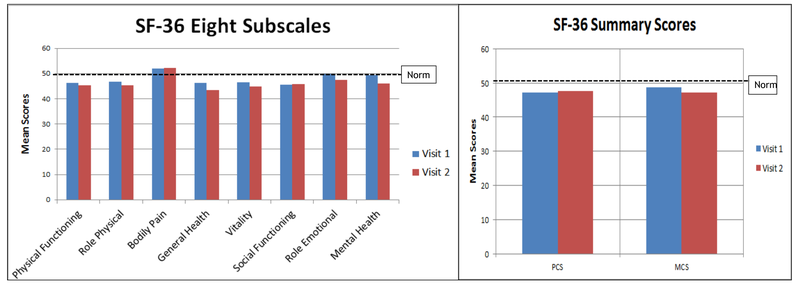
Results

Table 1: Patient Characteristics

Table I. Patient Characteristics

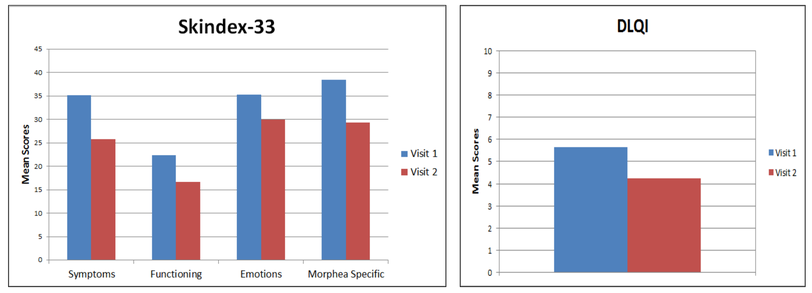
	N	%
Gender		
Male	19	17.3%
Female	91	82.7%
Ethnicity		
African American	2	1.8%
Caucasian	88	80.0%
Asian	3	2.7%
American Indian	0	0.0%
Hispanic/Latino	12	10.9%
Other	5	4.5%
Age (mean)	48.3	
Employment status		
Employed	35	31.8%
Unemployed	67	60.9%
Unavailable	8	7.3%
Insurance		
No Insurance	21	19.1%
Public	69	62.7%
Private	12	10.9%
Unavailable	8	7.3%
Income		
Less than $10,000	0	0.0%
$10,000-50,000	41	37.3%
$50,000-100,000	62	56.4%
Over $100,000	7	6.4%
Morphea subtype		
Plaque	16	14.5%
Linear	35	31.8%
Generalized	59	53.6%

Figure 1: Quality of Life in MAC cohort lower than normal population as measure by the Short Form-36



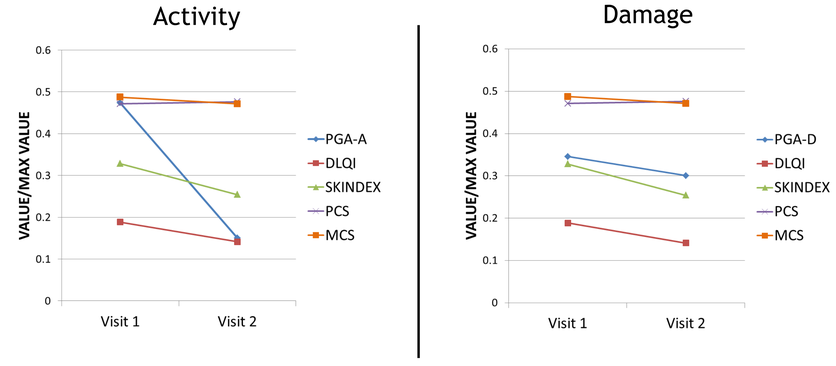
SF-36 is scored such that increasing values indicate an increase in quality of life measures. Scores are calibrated such that 50 is the norm to allow for comparison.

Figure 2: Quality of Life Improved Over Time in MAC cohort as measured by the Skidex-33 and DLQI



Both the Skindex- 29 +3 and the DLQI surveys are scored such that higher score indicate poorer QoL measures. The Skindex- 29 + 3 scores range from 0-100, DLQI scores range from 0 to 30.

Figure 3: Physician Scores vs Patient-Reported QoL reveal a decrease in disease severity does not indicate an improved patient quality of life



Conclusions

A decrease in disease severity does not mean an improvement in QoL. Lesions often don't disappear even as they transition to inactivity but rather leave frequent permanent sequalae. This indicates a need for further studies examining treatment of residual cosmetic and functional sequalae.

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