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Concerns about self-image in Northeastern Thai patients with systemic sclerosis

Sarita Panthongviriyakul[1], Papan Vadhanavikkit[1], Pongsatorn Paholpak[1], Chingching Foocharoen[2], and Nawanant Piyavhakul[1,*]

[1]Brain and Mind Wellness Research Group, Department of Psychiatry, Faculty of Medicine, Khon Kaen University, Khon Kaen Thailand
[2]Scleroderma Research Group, Department of Medicine, Faculty of Medicine, Khon Kaen University, Khon Kaen, Thailand
[*]Corresponding author: nawanant@kku.ac.th

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Abstract

Systemic sclerosis (SSc) affects appearance and causes concerns about self-image. This study explored concerns about self-image in patients with SSc in Thailand. A total of 100 patients with SSc completed a Brief-Satisfaction with Appearance Scale (brief-SWAP), a self-report questionnaire assessing subjective dissatisfaction and perceived social impact from concerns of self-image, and the Thai Hospital Anxiety and Depression Scale (Thai HADS). The participants included 69 females and 31 males with a mean age of 60.3 ± 7.3 years. Diffuse cutaneous SSc accounted for 67% with a median of disease duration of 5.9 years. The mean score of the brief-SWAP was 18.1 ± 8.4. Mild and moderate depression were found in 14% and 3%, respectively. Mild and moderate anxiety were found in 16% and 7%, respectively. Analyses found the significant predictive regression model for the brief SWAP ($p< 0.001$, $R^2 = 0.221$) with following predictors: HADS anxiety subscale, ischemic ulcers, and skin involvement on the hands/fingers (all $p<0.05$). For subjective dissatisfaction, the significant regression model ($p< 0.05$, $R^2 = 0.186$) showed the following significant predictors: the amount of the daily dose of prednisolone and ischemic ulcer. For perceived social impact, the significant regression model ($p< 0.001$, $R^2 = 0.378$) had the following significant predictors: the HADS anxiety sub-scale and hand deformities. Concerns about self-image in patients with SSc were significantly correlated with levels of anxiety and with areas of skin involvement. Patients having ischemic ulcers showed a higher level of concern regarding self-image and should be carefully assessed for psychological well-being.

Keywords: Systemic sclerosis, Scleroderma, Self-image

1. Introduction

Systemic sclerosis is a chronic autoimmune disease in which fibroblasts create excessive collagen in both the skin and internal organs. The etiology of the disease remains unclear. In the northeastern region of Thailand, the incidence is about 1: 100,000 with female to male ratio of 2:1. The most affected population ranged in age from 40-50 years [1].

People with systemic sclerosis usually present with skin tightness, and hand contracture, while some patients even have digital ulcers and Raynaud's phenomenon. Systemic sclerosis can involve multiple organ systems, including the respiratory system, the cardiovascular system, and gastrointestinal tract. Skin manifestations are prominent signs and symptoms of systemic sclerosis. In the early stages, patients may have edematous skin, which later turns into skin tightness due to excessive collagen production. Facial involvement of skin tightness may occur, including a limited ability to open the mouth; while others experience hyperpigmentation with the appearance of salt and pepper skin, in which the most affected areas are on the neck, chest, and the upper back [2]. Therefore, these features of skin involvement not only cause disability, but also affect self-appearance in a negative way [3].

A retrospective cohort from 2009-2019 [4] showed a 10-year survival rate up to 93%. The best prognosis for mortality was found in females with late onset and early treatment. These changes in appearance may cause self-image dissatisfaction and social discomfort. Depression and anxiety have been found to be more common in patients with systemic sclerosis than in the general population [5]. Western countries have studied the impact of mental health and self-image toward appearance. They found that some factors, such as gender, age, and disease progression, especially in visible areas like face and hands play a major role in determining self-image [6,7]. Dissatisfaction with appearance and social discomfort can cause anxiety and depression [8]. It is important to know the extent of problems with self-image, since it is associated with mental health, well-being, and the quality of life [5]. For instance, having digital ulcers was found to be associated with higher levels of disease burden in both occupational impairment and activities of daily life [9]. Home exercise has been shown to be a beneficial intervention in terms of improvement for pain, function, and depression [10]. However, issues with emotional and social spheres have not yet been explored in Thailand or in Asian populations.

2. Materials and methods

2.1 The participants

From the Scleroderma Clinic at Khon Kaen University's Srinagarind Hospital, a total of 100 patients with systemic sclerosis were recruited by using convenient sampling. The inclusion criteria were as follows:

1) Having been diagnosed with systemic sclerosis in accordance with the 2013 classification criteria for sclerod erma by the joint committee of the American College of Rheumatology (ACR) and the European League against Rheumatism (EULAR) (ACR/EULAR 2013)**.**
2) Being older than 18 years of age.
3) Being fluent in the Thai language.

The exclusion criteria were as follows:

1) Refusing to participate.
2) Having emergency medical conditions, which would have interfered with ability to complete an interview (e. g., renal crisis, severe pulmonary fibrosis).
3) Having been diagnosed with an overlapping syndrome associated with other rheumatologic disorders.

2.2 Sample size calculation

The sample size of 100 participants was expected in *a priori* to represent patients with systemic sclerosis and to explore the predictive factors of self-image satisfaction. This number of participants is generally considered to be the minimum sample size [11] when seeking to explore predictive factors with multivariate analyses.

2.3 Demographic data and primary outcome

Socio-demographic data, including sex, age, marital status, and level of education, were obtained. Permission to use the brief version of Satisfaction with Appearance Scale (brief-SWAP) was acquired from Dr. Lisa Jewett, who developed the scale [12]. The brief-SWAP was translated into Thai by the author, and the translated questionnaire was reviewed by three other psychiatrists from the Department of Psychiatry at the Faculty of Medicine at Khon Kaen University. The brief-SWAP quantifies the severity of self-image dissatisfaction from 6 questions which are 7-point Likert scales. The questionnaire was categorized into 2 domains as follows:

1) The Dissatisfaction with Appearance Subscale (DAS) with 3 items.
2) Social Discomfort Subscale (SDS) also with 3 items. The ratings for each question were as follows:

0 = strongly disagree; 1 = disagree; 2 = somewhat disagree; 3 = neutral; 4 = somewhat agree; 5= agree, and 6 = strongly agree. Each sub-scale consisted of 18 scores, while the overall brief-SWAP had a total score of 36. Higher brief-SWAP scores indicated a higher level of concern about self-image.

2.4 Secondary outcomes

Symptoms of anxiety and depression were measured by the Thai Hospital Anxiety and Depression Scale (Thai HADS), which is a self-reported 14-item questionnaire. The Thai HADS had 2 sub-scales, namely a depressive and an anxiety sub-scale with 7 questions for each sub-scale. Each question asks the respondents to rate the severity of their depressive and anxiety symptoms by asking for a positive emotion (e.g., "I still enjoy the things I used to enjoy.") or a negative emotion (e.g., "Worrying thoughts go through my mind."). The rating for each Likert scale question ranged from 0 – 3. The scoring of questions asking for negative emotion ranged from 0 ("not at all" or "no symptoms") to 3 ("very severe" or "very frequent"). The scoring of questions asking

for positive emotion was reversed and ranged from 0 (“most of the time” or “as much as it used to be”) to 3 (“not at all” or “hardly at all”). Each sub-scale score was categorized as having mild symptoms for scores of between 8-10 points; moderate symptoms for 11-14 points, and having severe symptoms for scores ranging between 15-21 points [13].

The clinical characteristics of systemic sclerosis were retrieved from the medical records as follows: weight, height, body mass index (BMI), the type of systemic sclerosis, the stage of systemic sclerosis, disease duration, Raynaud phenomenon, ischemic ulcers, digital gangrene, telangiectasia, salt and pepper skin, skin edema, skin tightness, hand deformities, weight loss, loss of libido, modified Rodnan skin score (mRSS), and the dosage of immunosuppressive treatment.

2.5 Statistics

Data with normal distribution was presented by frequency and by mean ± standard deviation, while median (interquartile ranges) were used to present data with non-normal distributions. In predictive analyses, the backward method was used in every linear regression analysis to determine the significant variables for brief SWAP and for both sub-scales. For regression analyses, a 95% confidence interval for B, standardized Beta coefficients, and t were presented. The cut-off for a statistically significant level was a $p< 0.05$. All analyses were performed using IBM SPSS Statistics Version 25.

3. Results

3.1 Demographic data and disease characteristics

Data from a total of 100 participants (100%) was included into the final analyses. Details of the characteristics of the participants and the disease are presented in the Table 1. The most common medical comorbidities had been dyslipidemia (30%), hypertension (22%), and kidney disease (13%). Other than prednisolone, the other immune modulators, which were used, had been hydroxychloroquine (26%), mycophenolate mofetil (13%), cyclophosphamide (12%), Methotrexate (7%), and azathioprine (3%).

Table 1 The demographic, characteristic, and psychological status data of participants (N = 100).

Variables	N (%)	Mean ± SD/ Median (IQR)
Socio-demographic data		
Sex		
-Female	69 (69)	
-Male	31 (31)	
Age (years)		60.3 ± 7.3
Marital status		
- Married	80 (80)	
- Widowed	17 (70)	
- Single	3 (3)	
Educational level		
- Primary	61 (61)	
- Secondary	13 (13)	
- Above a bachelor’s degree	20 (20)	
Characteristics of systemic sclerosis		
Disease duration (years)		5.9 (2.2-11)
Types of SSc		
- Limited	33 (33)	
- Diffuse	67 (67)	
Stages of SSc		
- Atrophic	51 (51)	
- Indurative	41 (41)	
- Edematous	8 (8)	
mRSS		3 (0-10)
Raynaud’s phenomenon (yes)	53 (53)	
Skin tightness (yes)	49 (49)	
Hand deformities (yes)	38 (38)	
Salt and pepper skin (yes)	33 (33)	
Telangiectasia (yes)	30 (30)	
Ischemic ulcers (yes)	18 (18)	
Skin edema (yes)	8 (8)	
Loss of libido (yes)	73 (73)	
Weight loss (yes)	15 (15)	
Daily dose of prednisolone (mg/d)		1 (0-5)
Psychological status		
Total brief-SWAP		18.1 ± 8.4
- DAS		10 (6-14)
- SDS		8 (4-12)
Thai HADS		
- HADS depression		4 (2-6)
- HADS anxiety		5 (3-7)

(SSc = systemic sclerosis; SWAP = Satisfaction with Appearance Scale; SDS = Social Discomfort Subscale; DAS = Dissatisfaction with Appearance Subscale; HADS = Hospital Anxiety and Depression Scale; mRSS = modified Rodnan skin score; IQR = interquartile range; SD = standard deviation)

3.2 Self-image and psychological factors

Of the participants, 17% showed HADS depressive sub-scale scores that were higher than the cut-off of 8 indicating clinically significant depression. These participants were categorized into mild (14%) and moderate (3%) depression, respectively. In addition, 23% of the participants showed HADS anxiety subscale scores higher than the cut-off of 8 indicating clinically significant anxiety. These participants were categorized into having mild (16%) and moderate (7%) anxiety, respectively.

Linear regression analyses were performed to predict the total brief-SWAP, DAS, and SDS scores using the backward method. For each dependent variable, the entered variables in the first step of the regression analyses were selected from the results of the univariate regression analyses with $p< 0.2$. [14]. In the first step, the entered variables for the total brief-SWAP score were as follows: HADS anxiety subscale, HADS depressive subscale, ischemic ulcers, salt and pepper skin, and skin involvement on the hands/fingers. The variables entered in the first step for DAS were as follows: weight loss, BMI, level of education, ischemic ulcers, salt and pepper skin, Raynaud's phenomenon, total mRSS, chest/abdomen skin involvement, skin involvement on the legs/feet, and the daily dose of prednisolone. The variables entered in the first step for SDS were as follows: the type of SSc, the HADS anxiety subscale, the HADS depressive subscale, ischemic ulcers, salt and pepper skin, hand deformities, total mRSS, and skin involvement on the hands/fingers. The model with the highest R^2 value for each dependent variable with a significant *p*-value was selected as the predictive model. Significant predictive factors from the predictive models for total brief SWAP, SDS, and DAS are detailed in Table 2.

Table 2 Significant predicting factors from the regression analyses with self-image dissatisfaction scores.

N = 100	Unstandardized B	95% CI		Beta	t	*p*-values	R^2
Total brief-SWAP						0.000	0.221
HADS anxiety	0.60	0.02	1.18	0.22	2.07	0.040	
Ischemic ulcers	4.58	0.59	8.56	0.21	2.28	0.025	
Hands/fingers	2.26	0.41	4.10	0.24	2.43	0.017	
SDS						0.000	0.378
HADS anxiety	0.57	0.21	0.92	0.32	3.19	0.002	
Hand deformities	2.19	0.13	4.25	0.20	2.11	0.037	
DAS						0.048	0.186
Daily dose of prednisolone (mg)	0.36	0.04	0.68	0.27	2.24	0.028	
Ischemic ulcers	2.88	0.12	5.64	0.22	2.07	0.040	

(SWAP = Satisfaction with Appearance Scale; SDS = Social Discomfort Subscale; DAS = Dissatisfaction with Appearance Subscale; HADS = Hospital Anxiety and Depression Scale)

4. Discussion

To our knowledge, this was the first study in Thailand to investigate the impacts of systemic sclerosis on self-image satisfaction. It was found that the mean score of the brief-SWAP in our study had been higher than the previous study from Jewett et al [7] (18 ± 8.44 vs. 13.5 ± 8.8). Interestingly, the severity of mRSS in this study was found to be lower than the mRSS in that study (3 vs. 9). These findings highly suggest that a higher level of self-image dissatisfaction in patients with systemic sclerosis had not been solely driven by a higher degree of disease severity.

This study found that having digital ischemic ulcers and hand deformities had negatively affected self-image satisfaction. This finding supported results from a previous study by Jewett et al [7]. in which it was found that the severity of hand contracture measured by fingertip-to-palm distance had caused dissatisfaction with appearance. Results from this study and Jewett et al [7]. had also been in line with the finding that the extent of skin involvement had revealed significant correlations with self-image dissatisfaction. However, some of our findings differed from previous studies. Hand or finger involvement was found to be the most significant associated factor in this study, while Jewett et al [7]. found that a facial involvement had been the most significant factor associated with self-image dissatisfaction. According to a case-control study from Farhat et al. in France [15], about a half of the cases, who experienced physical discomfort, had been concerned with the face, while 27% had been concerned with the hands. Patients with perioral radiated wrinkles had a significantly higher perception of aesthetic impairment when compared to the visual aesthetic scale (AES). There had been no significant association between AES scores and digital ulcers, while there had been for pitting scars. However, telangiectasia was associated with a marginal difference of AES scores across groups. Our study also found that having telangiectasia had not negatively affected the SDS scores, unlike the results from Jewett et al and Ennis et al [6,7]. However, what had come across as interesting was that visceral involvement or disease-

specific organ manifestations had not significantly impacted the ways in which patients perceived their body image [15,16]

The major differences between this study and the previous studies were ethnicity and local weather in the studied regions. Farhat et al conducted their study in a single referral center in France. Most of the population from Jewett et al and Ennis et al [6,7] were Caucasians (91% and 96%, respectively), who were living in regions with cold weather, while the entire population in this study consisted of Asians, who were living in a studied region where the weather was hot and humid. It is possible that lesions in people with different skin colors may differently affect self-image dissatisfaction. Furthermore, wearing long sleeve clothes to conceal the lesions may be more suitable for people, who live in regions with cold weather. Therefore, it is possible that differences in the characteristics or the locations of the lesions may affect self-image dissatisfaction in various ways. Moreover, culture, ethnicity, skin color, and weather in each region may influence the ways in which people deal with self-image problems after having a lesion.

Regarding socio-demographic status, Kwakenbos et al [17] conducted a review and assumed that age and marital status had an impact on self-image. When compared to the older people, younger people tended to have poorer self-images. The author noted that the younger people may be more socially active because they would want to meet a lot more people to start relationships, while the older people were married and already engaged in stable relationships. In another study by van Lankveld et al [18], women had shown lower levels of self-esteem and lower self-image satisfaction levels than men. According to a review by Barsotti et al [19], women of working age had tended to have more appearance anxiety. Also, in the French cross-sectional study [16], the female gender was associated with anxiety symptoms. Due to the results of chronic and disabling illness, women with systemic sclerosis had been more likely to have fewer feminine interests and to exhibit social withdrawal by evaluating psychopathology using the Minnesota Multiphasic Personality Inventory-2 (MMPI-2) [20]. Benrud-Larson et al [21] conducted a study on 127 female patients with SSc and found that younger age, skin tightening above the elbows, and functional disability, had been related to body image dissatisfaction. The results from our study found that age, sex, educational level, and marital status were not significantly correlated to self-image, and as such, these results were found to be inconsistent with previous studies. This may be from a nature of our cohort, in which there was a predominance of middle-aged to elderly female members of the population.

Regarding depression and anxiety, the prevalence of clinically relevant depression and anxiety in our study had been 17% and 23%, respectively. These figures aligned well with a study conducted by Del Rosso et al [8], who also used HADS and found depression or anxiety in about 23% of the population. However, the prevalence from our study was much less than the prevalence from one systematic review in which the prevalence of depression ranged from 36 – 65% [22]. This discordance of prevalence may be explained by the different questionnaires used in each study, such as the Beck Depression Inventory (BDI), the Montgomery-Asberg Depression Rating Scale (MADRS), the Hospital Anxiety and Depression Scale (HADS), and the Center for Epidemiologic Studies Depression (CES-D) scale.

This study found that anxiety was significantly correlated with the degree of self-image dissatisfaction. This pattern of correlation was also noted in a previous study by van Lankveld et al and Farhat et al [15,18]. Moreover, this study also found that the daily dose of prednisolone had shown a significant effect on the DAS score, but had not shown a significant effect on the overall self-image dissatisfaction or SDS score. In this study, however, the maximum dose of prednisolone (15 mg/d) was considered to be low. This implied that the activity of the disease may have already subsided in most participants. Moreover, a low-dose of prednisolone in long-term treatment may not cause any disfiguring adverse effects.

In summary, this study reported that mild anxiety and depression had been common among patients with systemic sclerosis and could correlated with concerns about self-image. Those patients with ischemic ulcers, hand deformities, and skin involvement on the hands or fingers had been more likely to have a higher level of concerns about their self-image. This study had both its strengths and limitations. The major strengths included being the first study to be conducted on an Asian population with a moderate sample size. The major limitation stemmed from the fact that without a control group, there can be selection bias based on the nature of a cross-sectional study. There still is a lot of room for research in this area. The relationship between the course of disease progression and concerns about self-image in the long-term still remains to be explored. After screening and monitoring the degree of depression and anxiety in patients with systemic sclerosis, obtaining an understanding of the psychological aspects of these patients will be helpful in designing an early psychological intervention.

5. Conclusion

Mild anxiety and depression were found to be common in SSc. Anxiety had been correlated with concerns about self-image. It is crucial to screen and monitor patients with SSc for depression and anxiety. Patients, who have symptoms of ischemic ulcers, hand deformities, and skin involvement of the hands/fingers, are more likely

to have a higher degree of concern about their self-images and should be exclusively screened to assess their psychological well-being.

6. Ethical approval

This descriptive cross-sectional study, which was carried out between August and December of 2019, was conducted in accordance with the Declaration of Helsinki and the ICH Good Clinical Practice guidelines. The study was approved by the Khon Kaen University Ethics Committee for Human Research with #HE621155.

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