Original Article

Psychosocial Status in Turkish Scleroderma Patients: Hopelessness and Social Support

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Abstract

Background and aim: In patients with scleroderma, physical changes, musculoskeletal and organ involvement lead to emotional problems. This study was planned to determine the level of hopelessness and social support, as well as influencing factors, in scleroderma patients.
Methodology: The study was conducted as a descriptive study in 97 scleroderma patients. The study data were collected using the "Perceived Family/Friend Support Scale (PFSS)" and the "Beck Hopelessness Scale (BHS)".
Results: The mean BHS score of the participants was 6.9±5.6. The level of PFSS-friends was found to be higher in males and in those with a family history of rheumatological diseases ($p<0.05$). The level of PFSS-family was lower in those with a family history of miscarriage/stillbirth ($p<0.05$). A positive correlation was found between functional score and hopelessness, whereas a negative correlation was found with the social support scores ($p<0.05$). Moreover, it was determined that scores of hopelessness were decreased as the scores of social support were increased ($p<0.05$).
Conclusion: Patients need more social support as their functional status is impaired and they are driven more to hopelessness due to a sense of dependence and role loss.

Keywords: hopelessness, social support, scleroderma.

Introduction

Scleroderma is a connective tissue disease with potentially fatal outcomes. It causes skin thickening, ischemic ulcerations and damage to visceral organs such as lungs, heart and kidney due to inflammation, vascular damage and fibrosis (Haythornthwaite, Heinberg, & McGuire, 2003; Schouffoer et al., 2011).

It has been determined in a study in Turkey that the prevalence of scleroderma is 220 in a million and it is stated that the disease is observed more frequently among women in the age interval of 30-50 (Cakir et al., 2012).

Scleroderma is a multisystem disease with no effective treatment or cure. Scleroderma encompasses broad multidimensional issues, including biological, psychological, and social processes. Therefore, scleroderma has a potentially important economic impact in terms of health care costs and lost productivity (Lopez-Bastida et al., 2014).

Understanding the role of psychosocial phenomena while evaluating a chronic disease like scleroderma is of importance for many reasons. First, the process of coping with a chronic disease may cause significant physical and psychological impacts on the patient (Moser et al., 1993). Symptoms such as pain, disability and disfigurement which are related with scleroderma have negative effects on the perception by the patient of his/her insufficiency in carrying out the daily and personal activities as well as on house chores, work and leisurely activities (Haythornthwaite, Heinberg, & McGuire, 2003).

Negative behavior such as poor compliance with medical treatment, increasing social isolation and decrease in seeking social support are related with depressive symptoms. Scleroderma patients are under high risk of depression due to reasons such as chronic pain, fatigue, dissatisfaction with physical appearance and high disability level (Thombs et al., 2007).

Studies carried out indicate that anxiety and depression ratios in scleroderma patients is higher in comparison with the general population (Kwakkenbos et al., 2012; Del Rosso et al., 2013). It has been determined that the depressive symptoms in scleroderma patients are related with fatigue, social support, emotional coping, hopelessness and fear of the disease advancing (Kwakkenbos et al., 2012).

Scleroderma is different than other rheumatologic diseases due to the physical changes it causes in the individual. Observable parts of the body (like hands and face) are affected in this disease which is especially observed in young women. It is stated that the changes in the hands and face affect self-esteem and that low self-esteem is related with many psychological variables. In addition, it is also emphasized that the fear of the advancement of the disease has significant effects on the mental health of scleroderma patients which is in turn related with the psychosocial stress of these patients (Kwakkenbos et al., 2012; Del Rosso et al., 2013).

Social support plays an important role in managing the progression of a variety of chronic degenerative diseases. Social network ties may serve both health-protective and coping functions in chronically ill patients (Penninx et al., 1999; Dinicola et al., 2013). Social support acts as a cushion for disease-related stress and favourably influences health by effectively attenuating the physiological and psychological impacts of stressors (Moser et al., 1993). Chronic diseases like scleroderma have a deep impact on the social functioning of patients and may lead to impairment in interaction with friends/family and in marital relationships (Haythornthwaite, Heinberg, & McGuire, 2003). Patients are at risk of developing hopelessness in cases where they negatively perceive the disease and believe that they can do very little to change it (Dunn, 2005).

Positive social support not only reduces stress and depression, but also has the potential to enhance self-esteem, personal power as well as the perception of well-being (Winters, Cudney, & Sullivan, 2010).

In this respect, the present study was planned to determine the level of hopelessness and social support, as well as related factors in scleroderma patients.

Material and Methods

Procedure

The study was designed as a descriptive study was conducted on 97 scleroderma patients who had been diagnosed according to 1980 ACR criteria, followed in rheumatology outpatient

clinic, and who agreed to participate in the study (Subcommittee for scleroderma criteria of the American Rheumatism Association Diagnostic and Therapeutic Criteria Committee, 1980).

The study included patients aged over 18 years who were able to communicate and who had agreed to participate. Patients with other chronic or psychiatric diseases and those who had been treated as inpatients were excluded from the study. The approval of the ethics committee at medical faculty, as well as the consents of the patients were was obtained prior to the study.

Data collection tools

The study data were collected using a self-description form consisting of socio-demographic and clinical characteristics, as well as the "Beck Hopelessness Scale" developed by Procidano and Heller and adapted into Turkish by Seber and Durak along with the "Perceived Family/Friend Support Scale" adapted into Turkish by Eskin. Medical data were collected by the rheumatologist.

Visceral organ involvement were assessed by using hospital record of the patients.

Self-description form: This form was prepared by the researchers and it consisted of 7 questions which aimed to determine the socio-demographic characteristics such as age, gender, education, marital and working statuses, and disease-related characteristics such as smoking, history of miscarriage/stillbirth, the health history of the family and the disease duration of the patients.

Beck Hopelessness Scale: This 2-point Likert scale, for which a validity and reliability study of the Turkish version was performed by Durak *et al.* was developed by Beck et al. The scale consists of 20 items which are answered either as "Yes" or "No". The "Yes" option takes 1 point in 11 of these items whereas the "No" option takes 1 point in 9 of these items. The scale is evaluated over 20 points and the level of hopelessness is elevated as the score increases (Beck et al., 1974; Durak, 1994).

Perceived Family/Friend Support Scale (FFSS): This scale was developed by Procidano and Heller and was adapted into Turkish by Eskin. The Family and Friend Support scale consists of a total of 40 items, 20 items concerning perceived support from family and 20 items about perceived support from friends. The possible responses to each item are as "Yes", "Partially" and "No". Scores range between 0 and 40 and higher scores indicate a high level of perceived social support, whereas lower scores reflect a low level of perceived social support.

The alpha consistency coefficient of the scale found by Eskin was 0.85 for perceived social support from family and 0.76 for perceived social support from friends (Procidano & Heller, 1983; Eskin, 1993).

Scleroderma-specific indices: Skin involvement was assessed by "Modified Rodnan Skin Score" (Clements et al., 1995). Disease activity was assessed in accordance with the Valentini criteria. Patients with a score of 3 and higher were considered to have active disease (Valentini et al., 2001).

The "Disease Severity Index" developed by Medsger *et al.* (1999) for scleroderma was used to assess the severity of the disease. The functional index score developed by Silman *et al.* (1998) was used to assess the functioning of the patients. In addition, we used a 10 cm Visual Analog Scale where patients and physicians globally evaluated the disease activity separately.

Health Assessment Questionnaire: The health assessment questionnaire, used to assess the functional state relating to the disease, was modified by Pincus *et al.* (1983), and a validity and reliability study for Turkey was performed by Kucukdevesi *et al.* (2004).

The scale investigates eight activities with 20 questions. Each activity score is determined based on the highest score obtained from the questions in that specific group. The scores are then added and divided by eight to calculate the total score. The total score ranges between 0-3 and the higher the score, the higher the level of functional dependency.

Assessment of visceral organ involvement: Gastrointestinal system involvement was assessed by esophagography and endoscopy; cardiac involvement was assessed by electrocardiography, echocardiography, and right cardiac catheterization in patients who required it; respiratory system involvement was assessed by respiratory function tests and HRCT; and renal involvement was assessed by complete urinalysis and presence of microprotein in a 24 hour urine sample.

Data Analysis

Data were evaluated using the SPSS program. We used the mean average significance test for the difference between the two mean averages (Student's t test). In addition, we used the one way analysis of variance (one way ANOVA) in the statistical evaluation of the findings. Moreover, we used Kruskall Wallis, Mann Whitney U and Spearman correlation analyses for the nonparametric findings. Values over $P < 0.05$ were regarded as statistically significant.

Results

The mean age of the participants was 50.47±13.59 years, 88.7% were female, 91.8% were married, 88.7% were unemployed, 14.4% had a family history of disease, and 51.2% had a personal history of miscarriage/stillbirth. The type of the disease was diffuse in 52.6%, at least one visceral organ involvement was detected in 86.6% of the scleroderma patients, 62.9% of the patients had been using low-dose steroids, and the mean diagnosis time was 5.09±4.88 years (Table 1).

The mean BHS score of the participants was 6.9±5.6, whereas the mean score was 12.8±7.2 for perceived social support from family and 10.4±6.8 for perceived social support from friends (Table 2). Whilst there was no difference between gender and the mean scores of hopelessness and perceived social support from family, the mean score of perceived social support from friends was found to be significantly higher in males ($p<0.05$). Whereas hopelessness showed no significant difference between education levels, perceived social support from family and from friends was significantly higher in literate participant groups ($p<0.05$). Working status and disease type showed no relation with hopelessness or perceived social support from family and from friends. While there was no relationship between family history of disease and the mean scores of hopelessness and perceived social support from family, the mean score of perceived social support from friends was found to be significantly higher in those with family history of disease ($p<0.05$). It was determined that the mean score of perceived social support from family was significantly lower in participants with a history of miscarriage/stillbirth versus other patients ($p<0.01$), whereas mean scores of hopelessness and perceived social support from friends did not differ between the groups. However, there was no difference between visceral organ involvement and the mean score of hopelessness or social support ($p>0.05$).

Table 1: Distribution of organ involvement among disease types

Characteristics	Diffuse N (%)	Limited N (%)	Mixed N (%)
Age (years)	50.17 ± 13.39	51.1 ± 13.88	48.85 ± 15.22
Gender (men/women)	5 / 46	4 / 35	2 / 5
ANA, n (%)	45 (95.7)	30 (93.8)	7 (100.0)
Anti-Scl-70, n (%)	28 (58.7)	9 (28.1)	2 (28.6)
Anti-centromere, n (%)	7 (20.6)	13 (54.2)	2 (28.6)
Heart, n (%)	12 (23.5)	9 (23.1)	2 (28.6)
Lung, n (%)	42 (82.4)	19 (48.7)	4 (57.1)
Gastrointestinal system, n (%)	35 (68.6)	21 (53.8)	2 (28.6)
Finger flexion, n (%)	21 (42.9)	9 (23.1)	1 (14.3)
Digital ulcer, n (%)	16 (32.7)	14 (35.9)	1 (14.3)
Organ involvement, n (%)	48 (94.1)	31 (79.5)	5 (71.4)
Total	**51 (52.6)**	**39 (40.2)**	**7 (7.2)**

Table 2: Scores of hopelessness and social support according to certain characteristics of patients

Characteristics	N (%)	Hopelessness X ± SD	Family support X ± SD	Friend support X ± SD
Gender				
Male	11 (11.3)	6.45 ± 4.7	11.63 ± 7.9	15.27 ± 2.9
Female	86 (88.7)	7.01 ± 5.7	12.98 ± 7.1	9.86 ± 6.9
		Z = -0.023, P = 0.982	Z = -0.585, P = 0.559	Z = -2.222, P = 0.026
Education				
Literate	56 (57.7)	6.76 ± 5.31	14.08 ± 6.5	11.7 ± 6.1
Illiterate	41 (42.3)	7.1 ± 6.1	11.1 ± 7.8	8.7 ± 7.4
		T = -0.366, P = 0.715	T = 2.023, P = 0.046	T = 2.181, P = 0.032
Working status				
Employed	11 (11.3)	5.5 ± 4.3	11.2 ± 7.0	13.3 ± 4.0
Unemployed	86 (88.7)	7.1 ± 5.7	13.0 ± 7.2	10.1 ± 7.0
		Z = -.646, P = 0.519	Z = -1,100, P = 0.271	Z = -1.142, P = 0.253
Disease type				
Diffuse	51 (52.6)	7.0 ± 5.3	12.6 ± 7.6	10.5 ± 6.8
Limited	39 (40.2)	6.2 ± 5.7	12.8 ± 6.7	11.0 ± 6.5
Mixed	7 (7.2)	9.8 ± 7.0	13.8 ± 7.9	7.0 ± 8.2
		X^2 = 2.832, P = 0.243	X^2 = 0.217, P = 0.897	X^2 = 1.668, P = 0.434
Family history of disease				
Yes	14 (14.4)	5.8 ± 5.1	13.7 ± 7.6	15.0 ± 4.2
No	83 (85.6)	7.1 ± 5.7	12.6 ± 7.2	9.7 ± 6.9
		Z = -0.701, P = 0.483	Z = -1.070, P = 0.284	Z = -2.602, P = 0.009
Valentini score				
Active	35 (36.1)	7.5 ± 5.5	10.7 ± 6.9	12.4 ± 7.4
Inactive	62 (63.9)	6.5 ± 5.7	10.3 ± 6.9	12.9 ± 7.2
		Z = -1.036, P = 0.300	Z = -0.348, P = 0.728	Z = -0.337, P = 0.736
Pregnancy (n=84)				
Miscarriage/stillbirth (+)	43 (44.3)	6.8 ± 5.9	11.4 ± 7.4	9.9 ± 7.4
Miscarriage/stillbirth (-)	41 (42.3)	6.9 ± 5.4	14.7 ± 6.6	9.9 ± 6.6
		Z = -0.243, P = 0.808	Z = - 2.152, P = 0.031	Z = -0.040, P = 0.968
Organ involvement				
Yes	84 (86.6)	7.2 ± 5.5	12.6 ± 7.3	10.5 ± 6.7
No	13 (13.4)	5.2 ± 6.2	14.0 ± 6.6	10.0 ± 7.7
		Z = -1.707, P = 0.088	Z = -0.661, P = 0.508	Z = -0.106, P = 0.915
Total	97 (100.0)	6.9 ± 5.6	12.8 ± 7.2	10.4 ± 6.8

Table 3: Correlation between some characteristics of the patients and mean scores of hopelessness and social support

	Hopelessness		Social support from friends		Social support from family	
	r	p	r	p	r	p
Age	-0.059	0.564	-0.074	0.473	-0.058	0.571
Disease age	0.078	0.478	-0.022	0.833	0.130	0.203
Disease severity index	0.043	0.674	-0.024	0.817	-0.053	0.606
Valentini activity score	0.171	0.094	-0.023	0.823	-0.085	0.826
Functional score	0.308	0.002	-0.312	0.002	-0.235	0.020
Rodnan score	0.093	0.364	0.060	0.562	0.075	0.465
Hopelessness	-	-	-0.266	0.009	-0.241	0.017

A positive correlation was found between the functional index and HAQ scores of the participants and level of hopelessness, whereas a significant negative correlation was found with perceived social support from family and from friends ($p<0.05$). A significant negative correlation was determined between the level of hopelessness and level of perceived social support from family and from friends ($p<0.05$). No significant relationship was found between age, age at the onset of disease, Rodnan score, disease severity index and VAS scores and the levels of hopelessness and social support ($p>0.05$) (Table 3).

Discussion

Hopelessness is characterized by negative feelings and reduction motivation and expectations about the future. A sense of hopelessness may cause to a reduction of coping with problems (Sahin, Tan, & Polat, 2013). The present study found the mean score of hopelessness, which is one of the most important indicators of depression, to be 6.9±5.6. No study investigating the level of hopelessness in scleroderma patients was found in the literature. However, a study in cancer patients found the mean score of hopelessness to be 6.8±0.4 (Pehlivan et al., 2012). This indicates that scleroderma patients feel hopelessness as much as a patient who is considered to have a fatal disease like cancer.

Individuals have difficulty in performing routine daily activities when they incur much physical loss. This leads to focusing on the disease, symptoms of the disease and unfavorable effects, and brings along dissatisfaction with body image. Disease constrains the patients from participating in social, occupational and recreation activities. Moreover, patients consciously stay away from social activities due to the change in their physical appearance and this leads to further social withdrawal. The protection of social relations is quite important in facilitating compliance with scleroderma (Haythornthwaite, Heinberg, & McGuire, 2003; Thombs et al., 2007; Jewett et al., 2012). The present study found the mean score of perceived social support from family and mean score of perceived social support from friends to be 12.8±7.2 and 10.4±6.8 respectively. It is stated that the increase in the intensity of the symptoms observed in the hands and faces increase the distress level which in turn causes patients to feel more isolated (Amin et al., 2011). This supports the low perceived social support by our patients in the study. It was determined in the study by Pehlivan et al. (2012) carried out on cancer patients found that the mean score of perceived social support from family was 32.2±0.6. Compared with the study of cancer patients, this result suggests that the level of perceived social support from family was lower in scleroderma patients.

With regard to the level of hopelessness and level of perceived social support from family/friends according to the socio-demographic characteristics of patients, they displayed no difference with age, working status, disease type, disease duration, symptom duration, and disease severity index. The level of hopelessness and perceived social support from family did not differ between genders, whereas the level of perceived social support from friends was significantly higher in males. Physical appearance, age and clothes are the first things that attract attention during interpersonal relations. They prepare a place for the subject in the population and influence the opinions of other people about the subject. Many women who are not satisfied with their physical appearance and who are suspicious of their own abilities have social adherence problems due to a sense of insufficiency and lack of confidence (Rubenzik & Derk, 2009). This also supports the results of the present study because scleroderma may cause impairment in the general appearance of the patients. This result may be attributed to all female patients who are housewives and a likelihood of an inadequate circle of friends.

In the present study, perceived social support from family and from friends was found to be significantly higher in the literate patient group. This might have resulted from the patients' efforts to obtain more information and support from different sources about the methods for treatment of and adherence to the disease in line with the increase in education level.

With regard to the relationship between family history of scleroderma and the level of hopelessness and social support, perceived social support from friends was higher in those with a history of the disease. This indicates that families have difficulty in coping with the disease as the number of patients in the family increased and they become unable to give adequate support and thus, the patients seek more support from friends.

We found that perceived social support from family was significantly lower in the patients with a history of miscarriage/stillbirth. Having a child increases the family bonds among couples; the inability to have a child due to a disease may cause the patient to be blamed for this situation thus indirectly leading to a reduction in social support.

Scleroderma is a connective tissue disease involving many organ systems with impact on all aspects of an individual's life. It has a large involvement area including the skin, muscle-skeletal system, kidneys, lungs, heart and gastrointestinal system (Benrud-Larson et al., 2002). In the present study, the level of hopelessness was higher in the patients with scleroderma-related organ involvement versus the patients without organ involvement. Although the difference between the groups was not statistically significant, this indicates that the level of hopelessness is likely to increase as the number of involved organs increases.

Scleroderma-related pain, disability and dysmorphism unfavorably influences many fields of daily life such as personal care, housework and occupational/leisure time activities. Many physical, functional and morbidity-related alterations make scleroderma a disease difficult to cope with (Haythornthwaite, Heinberg, & McGuire, 2003). In the present study, a significant positive correlation was found between functional index and the level of perceived social support from family/friends and hopelessness. This suggests that the development of disease-related disabilities and the chronic course of the disease drive patients to hopelessness thus creating a need for more social support.

Factors that drive the subject to hopelessness include not only internal factors such as autonomy, self-esteem, independence and power, but also external factors such as lack of people around the subject that could give help and the subject's perception of this situation. Therefore, a subject with chronic disease needs to be supported, accepted and understood more than a normal healthy adult in order to re-establish his/her impaired balance and to solve health-related problems (Bayramova & Karadakovan, 2004). The results of our study support this.

Social support is one the most popular and preferred modes of coping with hopelessness (Sahin, Tan, & Polat, 2013). It was determined in the present study that the level of hopelessness significantly decreased as the level of perceived social support from family/friends increased. Patients focus more on the symptoms and the negative effects of the disease when the physical impairment level and the difficulties in carrying out daily activities increase due to scleroderma.

If the disease prevents the social, occupational and recreational functionality contributions, this may lead the patients to lose the opportunity to change their reactions related with the opinions of other people regarding their physical appearance. Social relations have protective effects against the decrease of depressive symptoms in scleroderma patients (Haythornthwaite, Heinberg, & McGuire, 2003). This supports the finding in our study that as the social support level of patients decreases the hopelessness levels increase at a statistically significant level.

The limitations of this study are that we didn't use a comparison group such as general or other rheumatologic diseases. In addition, there was no other study evaluating the hopelessness and social support between scleroderma patients so we used the results of a study that was conducted with other chronic diseases. It would be better to use another group of patients including other rheumatologic or chronic diseases for further studies. Further studies are required to verify these findings in different ethnic and large groups.

In conclusion, it was found that the level of hopelessness in scleroderma patients is as high as those of cancer patients and that their level of social support is low. It is thought that psychological problems like hopelessness might be decreased in patients who receive adequate support since physical and psychological states would be favourably influenced. Informing the patient, family and population about this subject is important. The patient's family/friends should be informed that patients have substantial functional loss and need social support, and the patient should be provided with adequate support. The evaluation of mental or behavioural problems that accompany physical diseases is important since such mental or behavioural problems have negative effects on the adaptation of the patient, quality of life, mortality and morbidity.

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