



Case Report

Psychosocial effects of systemic sclerosis: A case report

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ABSTRACT

“...Sit down. Look at the TV. Move slowly. Wait for death.”

Background & Aim: Systemic sclerosis or scleroderma is a rare chronic connective tissue disease included among autoimmune rheumatic diseases. The disease affects many organs and the organ system. It also has multiple effects on the patient's individual life. In care management, in addition to the physical effects of the disease, its emotional, psychological, and social influences must also be considered and managed. The present study aimed to touch the psychosocial aspect of scleroderma and the unseen effects of the disease are presented over a case study.

Case Report: 52-year-old, female patient, married with two children. Her self-evaluation after the diagnosis of the disease, she explained that her physical state, social relationships, economic condition, domestic relations, and mood were affected by the disease negatively.

Conclusion: In managing psychosocial problems in nursing care, it is necessary to consider that each patient has different needs, perspectives on life, future expectations, and coping mechanisms. The present study reveals the unknown face scleroderma, its psychosocial effects, from a patient's point of view.

Introduction

Human is a whole with his biological, psychological, and social aspects. Imbalances in the interaction of these aspects with each other damage health, cause disease, or deteriorates an existing situation (1). Chronic diseases affecting the individual in multiple ways have multiple effects on the individual's life as well. The individual has to deal not only with the inabilities in physical functions but also with the loss of self-esteem, changing roles and relationships, future anxiety and changes of emotional state brought about by the disease (2).

Systemic sclerosis (SSc) is an autoimmune disease characterized by vascular damage and typical collagen accumulation in tissues (2). The incidence and prevalence of systemic sclerosis show significant differences between ethnic and regional factors. The prevalence of SSc was estimated at 0.0007–0.113% in both sexes in

the world (3,4). SSc seems to be consistently more frequent in the United States and Australia as compared to Europe and Japan (4). Çakır et al. (2012) estimated the prevalence of systemic sclerosis: 0.022% among the women and 0.011% in both sexes in western Turkey (3). While no current treatment can cure the disease completely, it is possible to enable most scleroderma patients to lead a more comfortable life with appropriate therapy and care. Skin tightening, contractures, and visceral involvements affect morbidity and mortality seriously. In addition to this, because of the changes, it leads to body image and perception; the disease affects overall quality of life for many reasons such as causing significant psychological problems, affecting economic conditions, resulting in losses in business (2, 5).

As in all chronic diseases, the responsibility of the nurse in taking care of a scleroderma patient is to plan and manage the patient's care by considering him/her as a bio-psycho-socio-cultural whole. Since the results of the disease and treatment come out not only at the physical level but also at

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emotional and social levels, it is critical to deal with and reveal all these components (6, 7).

The present study touches on the psychosocial aspect of scleroderma and the unseen effects of the disease are presented over a case. The data were collected through face-to-face interviews. A patient evaluation form was used including socio-demographic characteristics, information related to the disease, and data concerning the assessment of the effects of the disease on quality of life.

Also, to be able to display the psychosocial effects of the disease, the patient was asked to sincerely express the effects of being ill on her life and her thoughts about the feature. Responses were recorded by a tape recorder and were written down by the researcher with fidelity to the original data. During this process, the patient was provided with an environment where she could feel comfortable.

Case report

Defining characteristics of the patient are presented in Box 1. The patient was selected because she was able to express herself clearly and a volunteer.

Box1. Defining characteristics

<p>Socio-demographic characteristics: 52-year-old, female patient, married with two children, university graduate, unemployed, income equal to the expense</p>
<p>Information related to the disease</p>
<p>Period of diagnosis: 6 years</p>
<p>The course of the disease (Accompanying findings): Raynaud phenomenon, skin ulcers, shortness of breath, difficulty swallowing, gastrointestinal problems, oral and dental problems</p>
<p>Individual overall health evaluation: Moderate level</p>
<p>Self-evaluation of the effects of disease on quality of life: When the patient was asked about her self-evaluation after the diagnosis of the disease, she explained that her physical state, social relationships, economic condition, domestic relations, and mood were affected by the disease negatively.</p>

The patient's opinions about the effects of being sick on her life and her thoughts about

the future are presented with no interpretation.

Living with the disease

The patient has defined the effects of the disease using the following expressions.

- "I ask myself if this is me whenever I look at myself."
- "Is it me in this body? Although I try to take good care of myself, you can tell my unwillingness all over me; it feels as if this is not me."
- "The looks, the pity around me, it tears me apart, I do not want to see people often."
- "Whenever I look at my kids, I see that I am not sufficient as a mother."
- "Being a sick mom and wife casts me down."
- "I cry out against this disease, which limits my mobility very much for finding me."
- "I feel like a bomb ready for crying at any moment."
- "Sometimes, I think this is a dream; it's more depressing to wake up immediately and see the reality."
- "My hands get very bad at cold weather; I do not want to go out."
- "Being unable to swim in the sea, being unable to walk around the bazaars, looking more at pajamas, feeling jealous of lively people laughing when I go out..."

Thoughts about the future

The patient stated her future expectations with the following expressions.

- "I know I might be like a creature everybody looks at strangely, a creature that can more or less take care of herself at home, with a wrinkly face, curled fingers, problematic feet, dark-colored skin."
- "I do not want people to be afraid of me, particularly my grandchildren if I can see them."
- "I think, I am sure this life will be monotonous from now on; sit down, look at the TV. Move slowly. Wait for death."

Evaluating the patient's expressions, it can be seen that the changes in physical appearance caused by scleroderma affect the

patient's self-esteem, body perception, and body image. The patient's opinions about and attitudes towards the appearance of herself and others seem to be influencing her profoundly. Changes occurring in her self-esteem and image affect her social life and cause her to isolate herself from social life. Physical disabilities caused by the disease make it hard to fulfill her roles in the family, the thought that she fails to be a good mother and wife leads to grief and a feeling of uselessness. The patient expressed her grief for being unable to live like healthy people. It is seen that the individual still asks the question "Why me?" in this process and compares herself with others. It is possible to see the effects of being unable to lead her life like others and to do the things she wants.

In the patient's expressions related to her future, her concerns about her body image stand out. The patient's hopelessness and despair are reflected in her expression "...Sit down. Look at the TV. Move slowly. Wait for death."

After the interview, the patient stated the importance of expressing herself by saying, "It feels good to express my situation without feeling any anxiety or shame."

Based on the patient's expressions, hopelessness, lowered self-esteem, deteriorated body image, change in role relationships (mother-wife), breakdown in social relationships, social isolation, anxiety, fear, grief, and ineffective coping nursing diagnoses were detected.

Discussion

The fact that the disease has multiple dimensions, that is, it affects many organs, and the organ system increases the problems experienced by the individuals with scleroderma and may decrease their quality of life at a significant level (1). In a study carried out with patients with scleroderma, it was found that out of the problems faced because of the chronic and progressive character of the disease, 14% were psychological problems and 71.4% were problems in social activities (8).

Symptoms are experienced from mild to severe throughout the disease. The patient

may experience feelings of fear, depression, sorrow, anger, and denial. This needs to be managed carefully (9). The most important diagnostic finding in SSc is skin sclerosis (e.g., hands, neck, face, mouth). The changing appearance and disabilities in the course of the disease damage body image while adversely affecting the individual's self-esteem.

Moreover, findings of anxiety and depression resulting from living with a chronic disease are included among the factors affecting self-esteem (10, 11). Chronic diseases which deplete personal and social resources lead to imbalances and stress within the family. Family changes during the disease as well. In this process, problems of ineffective coping, changes in role performance, impairment of sexual life, decrease/difficulty in care-giving roles, and insufficiency in social support may occur. Chronicity of the disease, hospitalization, emotional, and social difficulties threaten family integrity and social relationships (12, 13).

As in all chronic diseases, social support is essential in scleroderma, too. The presence of community-based support organizations is beneficial to patients. Effective coping is the key to self-care. Cognitive-behavioral support programs and programs that promote positive body image can help improve practical coping skills. In addition to all these, it is considered that providing patients with the opportunity to share their life experiences and express themselves can help patients to increase their awareness and to feel relieved.

Conclusion

SSc is a rare disease. Currently, there is no cure for scleroderma. Therefore, it is critical to plan patient care and disease management. In the nursing care of a scleroderma patient, the nurse's role is not only limited to physical care, but it also involves approaching the patient holistically considering the psychosocial effects of the disease. The most crucial fact in approaching a patient with scleroderma is that each patient has different life experience with the disease. In managing

psychosocial problems in nursing care, it is necessary to consider that each patient has different needs, perspectives on life, future expectations, and coping mechanisms. Psychosocial care needs can be unobserved in the nursing care plan, particularly in rare diseases like scleroderma. It is hoped that this case will generate understanding and insight for future nursing practices.

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Conflict of Interest

The authors declare that there are no conflicts of interest regarding the publication of this paper.

References

1. Špiritović M. Biopsychosocial Aspects in Management of Scleroderma Patients. In: *New Insights into Systemic Sclerosis*. Tomcik M, editor. Intechopen Publishing, London, 2019. DOI: <http://dx.doi.org/10.5772/intechopen.86220>. Available from: <https://www.intechopen.com/books/new-insights-into-systemic-sclerosis/biopsychosocial-aspects-in-management-of-scleroderma-patients>.
2. Ryan S. The Psychological Aspects of Rheumatic Disease. In: *Rheumatology Nursing: A Creative Approach*. Hill J, editor. Whurr Publishers Limited (a subsidiary of John Wiley & Sons Ltd), England, 2006, p: 151-172.
3. Çakır N, Pamuk ÖN, Derviş E, İmeryüz N, Uslu H, Benian Ö, Elelçi E, Erdem G, Sarvan FO, Şenocak M. The prevalences of some rheumatic diseases in western Turkey: Havsa study. *Rheumatology international*. 2012 Apr 1;32(4):895-908. <https://doi.org/10.1007/s00296-010-1699-4>
4. Ranque B, Mouthon L. Geoepidemiology of systemic sclerosis. *Autoimmunity reviews*. 2010 Mar 1;9(5):A311-8.
5. Tokem Y, Özel F. Skleoderma ve Hemşirelik Bakımı. *Ege Üniversitesi Hemşirelik Dergisi*, 2011;27(2): 79-88.
6. Bayındır SK, Biçer S. Holistik Hemşirelik Bakımı-Holistic Nursing Care. *İzmir Kâtip Çelebi Üniversitesi Sağlık Bilimleri Fakültesi Dergisi* 2019; 4(1): 25-29.
7. Yılmaz M. Kronik Hastalıklarda Psikososyal Faktörler. In: *Temel İç Hastalıkları Hemşireliği ve Farklı Boyutlarıyla Kronik Hastalıklar*. Ovayolu N, Ovayolu O, editors. Çukurova Nobel Tıp Kitabevi. Adana 2017, p: 600-604.
8. Sierakowska M, Sierakowski S, Lewko J. Nursing problems of patients with systemic sclerosis. *Advances in Medical Sciences*; 2007, 52 (suppl. 1), 147-152.
9. Battle LH, Aiken LI. Scleroderma: Managing patient care. *Nursing made Incredibly Easy*. 2018 Jan 1;16(1):21-4.
10. Kwakkenbos L, Delisle VC, Fox RS, Gholizadeh S, Jewett LR, Levis B, Milette K, Mills SD, Malcarne VL, Thombs BD. Psychosocial aspects of scleroderma. *Rheumatic Disease Clinics*. 2015 Aug 1;41(3):519-28. <https://doi.org/10.1016/j.rdc.2015.04.010>.
11. Thombs BD, Van Lankveld W, Bassel M, Baron M, Buzza R, Haslam S, Haythornthwaite JA, Hudson M, Jewett LR, Knafo R, Kwakkenbos L. Psychological health and well-being in systemic sclerosis: state of the science and consensus research agenda. *Arthritis care & research*. 2010 Aug;62(8):1181-9. <https://doi.org/10.1002/acr.20187>.
12. Oksel E, Gündüzoğlu NÇ. Investigation of life experiences of women with scleroderma. *Sexuality and Disability*. 2014 Mar 1;32(1):15-21. <https://doi.org/10.1007/s11195-013-9334-4>
13. Moots RJ. Manifestations of systemic sclerosis necessitate a holistic approach to patient care: a case report. *Musculoskeletal care*. 2010 Sep;8(3):164-7. <http://dx.doi.org/10.1002/msc.179>