

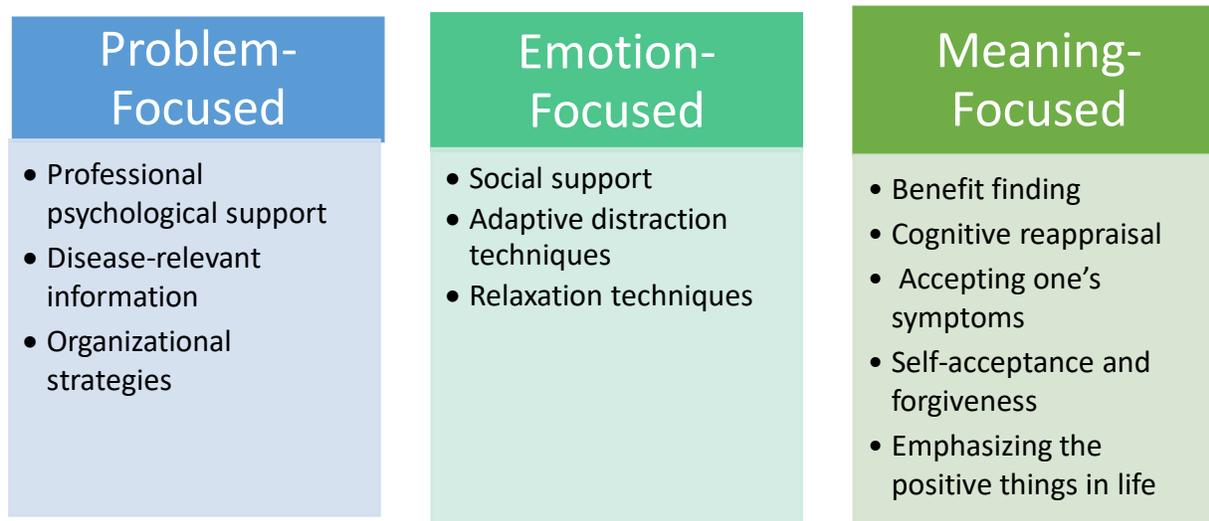
Living and Coping with Scleroderma

By: Kelly Bedner, University of Michigan, MPH Student

Do you know someone that has a chronic illness? Have you watched someone lose their quality of life because of this illness? Have you experienced grief due to losing someone to this illness? I think we have all been in this position, and it is a sad feeling. With that being said, I would like to talk about one specific chronic disease, [Scleroderma](#), and in more detail, the strategies to cope to improve one's quality of life.

Pain has been said to be the primary link to other stressors that these individuals experience. Besides negatively affecting patients physically, the disease also affects them psychosocially. Several of these psychosocial factors include depression, anxiety, social and sexual adjustment, employment, and body image distress. (Benrud-Larson, 2002) Therefore, due to scleroderma being a highly distressing disorder that ultimately affects the daily function and quality of life of these patients, it is important for them to have [coping strategies](#) that enhance their physical and mental well-being.

Three Categories of Coping Strategies



(Gumuchian, 2018)

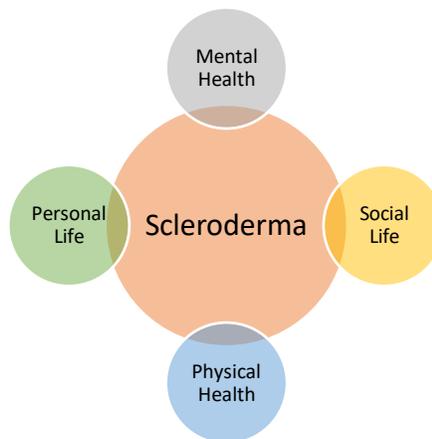
Social Support/Network

One of the most important factors for coping with scleroderma is social support. Those with close social relationships found that having emotional, informational, and instrumental support allowed them to be better equipped to face the various challenges associated with the disease. (Millette, 2020) "Social relationships can protect the individual from declines in function and social isolation predicts mortality." (Benrud-Larson, 2002) A common example is marital status, in

terms of having a supportive or distressed marriage. A distressed marriage was found to indirectly affect the health of scleroderma patients. (Haythornthwaite, 2003)

Patient Education and Cognitive Behavioral Interventions.

In order for scleroderma patients to cope with their illness, it is very important for them to have informational and educational programs, which may lead to improved satisfaction with services. Strategies related to patient education include telephone interventions, which help increase compliance with medical advice, and self-help interventions, which combine some professional contact with written or oral instructional materials. Furthermore, more recent programs that have been implemented include behavioral changes and self-management. (Haythornthwaite, 2003) Due to the feeling of helplessness and perceived lack of control, cognitive-behavioral (CB) interventions can be incorporated into one's life. CB interventions "assume that perceptions and evaluations of life experiences affect the individual's emotional and behavioral reactions to these experiences." (Haythornthwaite, 2003) Components of these interventions include relaxation, restructuring of cognitions, and biofeedback. Both are cost-effective strategies. When using self-management strategies, skills and resources for the patient to better cope with the daily challenges associated with their disease should be incorporated. These include those that relate to medical, emotional, and social role management. (Milette, 2019) For example, these include education that relates to the disease and its treatment, and education to support exercise, nutrition management, stress management and emotion regulation. (Milette, 2019)



Active Coping Strategies

Many scleroderma patients engage in active and passive coping strategies, in various forms. Some of these include trips into nature, listening/playing music, television, reading, gardening, traveling, caring for pets, cooking, meditation, etc. Other strategies include religious types, such as praying and attending church services. (Pilch, 2016)

Health-Care Related Support/Resources

Health care-related barriers exist with scleroderma, and this most likely makes coping with the disease more difficult than other chronic diseases. Common barriers include limited number of trained professionals and available treatment options. Other challenges related to healthcare also include accessing information and resources. (Milette, 2019) In order to overcome these challenges, it is important for these patients to have support from healthcare professionals. Support from these professionals include connecting patients to scleroderma organizations, support groups, and in general, seeking out local resources that relate to the disease. (Milette, 2019)

Many factors are involved in the disease, including both visible and invisible signs.

“Some patients have the disease more severe than others, which may create a higher distress, making them more vulnerable to poorer mental and physical health.” (Thombs, 2008)

This results in fear from the patients and negative reactions among those who don't understand. (Joachim, 2003) For example, one study found that the perception of being “ugly” to themselves and others was associated with greater fear than dying from the disease. (Amin, 2011)

With the disease itself and the future of one's life being unpredictable, factors that promote adjustment are necessary. Dispositional optimism plays a significant role in this. (Szramka-Pawlak, 2013) One study has shown that:

“individuals who are high in hardiness and believe that one is in control, that commitment to goals will result in positive outcomes, and that stressors are challenges, show better psychosocial adjustment to scleroderma.” (Haythornthwaite, 2003)

In other words, these patients have a sense that life's challenges are manageable and meaningful. Scleroderma may not have the same level of support as other chronic diseases do, so including knowledge, coping resources, and problem-solving skills should be incorporated into each patient's daily routine. (Joachim, 2003)

References

1. Amin, K., Clarke, A., Sivakumar, B., Puri, A., Fox, Z., Brough, V., Denton, C.P., Peter, E.M., & Butler, M.D. (2011) The psychological impact of facial changes in scleroderma, *Psychology, Health & Medicine*, 16:3, 304-312, DOI: [10.1080/13548506.2010.540250](https://doi.org/10.1080/13548506.2010.540250)
2. Benrud-Larson, L., Haythornthwaite, J., Heinberg, L.J., Boling, C., Reed, J, White, B., & Wigley, F.M. The impact of pain and symptoms of depression in scleroderma, *Pain*: February 2002 - Volume 95 - Issue 3 - p 267-275
doi: [10.1016/S0304-3959\(01\)00409-2](https://doi.org/10.1016/S0304-3959(01)00409-2)
3. Gumuchian, S.T., Peláez, S., Delisle, V.C., Carrier, M.E., Jewett, L.R., El-Baalbaki, G., Fortune, C., Hudson, M., Körner, A., Kwakkenbos, L., Bartlett, S.J., & Thombs, B.D. (2018) Understanding coping strategies among people living with scleroderma: a focus group study, *Disability and Rehabilitation*, 40:25, 3012-3021, DOI: [10.1080/09638288.2017.1365954](https://doi.org/10.1080/09638288.2017.1365954)
4. Haythornthwaite J.A., Heinberg L.J., & McGuire L. Psychologic factors in scleroderma. *Rheum Dis Clin North Am*. 2003 May;29(2):427-39. doi: [10.1016/s0889-857x\(03\)00020-6](https://doi.org/10.1016/s0889-857x(03)00020-6). PMID: 12841303.
5. Joachim, G. and Acorn, S. (2003), Life with a rare chronic disease: the scleroderma experience. *Journal of Advanced Nursing*, 42: 598-606. doi:[10.1046/j.1365-2648.2003.02663.x](https://doi.org/10.1046/j.1365-2648.2003.02663.x)
6. Milette, K., Thombs, B.D., Dewez, S., Körner, A., & Peláez, S. (2020) Scleroderma patient perspectives on social support from close social relationships, *Disability and Rehabilitation*, 42:11, 1588-1598, DOI: [10.1080/09638288.2018.1531151](https://doi.org/10.1080/09638288.2018.1531151)
7. Milette, K., Thombs, B.D., Maiorino, K., Nielson, W.R., Körner, A., & Peláez, S. (2019) Challenges and strategies for coping with scleroderma: implications for a scleroderma-specific self-management program, *Disability and Rehabilitation*, 41:21, 2506-2515, DOI: [10.1080/09638288.2018.1470263](https://doi.org/10.1080/09638288.2018.1470263)
8. Pilch, M., Scharf, S.N., Lukanz, M., Wutte, N.J., Fink-Puches, R., Glawischnig-Goschnik, M., Unterrainer, H.-F. and Aberer, E. (2016), Spiritual well-being and coping in scleroderma, lupus erythematosus, and melanoma. *JDDG: Journal der Deutschen Dermatologischen Gesellschaft*, 14: 717-728. doi:[10.1111/ddg.12715](https://doi.org/10.1111/ddg.12715)

9. Szramka-Pawlak, B., Dańczak-Pazdrowska, A., Rzepa, T., Szewczyk, A., Sadowska-Przytocka, A., & Żaba, R. (2013) Health-related quality of life, optimism, and coping strategies in persons suffering from localized scleroderma, *Psychology, Health & Medicine*, 18:6, 654-663, DOI: [10.1080/13548506.2013.764461](https://doi.org/10.1080/13548506.2013.764461)
10. Thombs, B.D., Hudson, M., Taillefer, S.S., & Baron, M. (2008), Prevalence and clinical correlates of symptoms of depression in patients with systemic sclerosis. *Arthritis & Rheumatism*, 59: 504-509. doi:[10.1002/art.23524](https://doi.org/10.1002/art.23524)