

Organization: Scleroderma Foundation
Authors: Ruby Hickman and Mitchell Schrank

Mental Health in Scleroderma: A Neglected Problem Worsened by COVID-19

Scleroderma is defined by its effects on the body such as tightening of skin and joints pain, but the broader impacts of scleroderma are much farther reaching. In particular, people with scleroderma are more likely to experience a range of mental health problems than the general population. Scleroderma, like other chronic diseases such as heart disease, cancer, and diabetes, requires continuous medical care and/or changes or restrictions to daily routines (*About Chronic Diseases*, 2020). When living with a chronic disorder, it is especially important to understand and address potential mental-health-related quality of life issues. Scleroderma, in particular, is a disease where attention to mental health has been less than ideal.

It is common for people with a chronic medical condition to face more problems with mental health than people without chronic conditions, and this holds true for people with scleroderma. An expert panel reviewing evidence on mental health and well-being in people with systemic scleroderma in 2010 found that scleroderma has many broader impacts on quality of life. An estimated 36-65% of people with systemic scleroderma report enough depressive symptoms to be of concern for a depressive disorder (Thombs et al., 2010). The panel also reported that fatigue, pain, body-image issues, and concerns such as fear of the future or the feeling of being dependent on others were issues that impact mental-health-related quality of life for many people with scleroderma.

Research on ways to improve mental health in persons living with scleroderma is limited. Some researchers have recommended that scleroderma care include attention to mental health and connection with resources such as phone-based peer support or online resources, and others have investigated cognitive-behavioral self-help (Thombs et al., 2012, Szramka-Pawlak et al.,

2013). However, the reality is that the little research and attention on mental health in scleroderma means that it is still up to the patient to monitor and address their mental health concerns.

Patients have even more setbacks for coping with scleroderma during a worldwide pandemic. Many patients with scleroderma take a type of drug called immunosuppressants to treat their condition. However, these drugs also increase the risk of getting infections, including coronavirus. Patients with lung issues are at higher risk for complications of COVID, a respiratory virus, and also may have issues finding the medication tocilizumab (TCZ), which is used in COVID patients with pneumonia (Orlandi et al., 2020). Ultimately, the pandemic's impact on scleroderma patients' physical health is crucial to address.

Indeed, it is also important to highlight the emerging role of the COVID-19 pandemic with respect to scleroderma patients' mental health. COVID-19 clearly impacts the mental health of individuals throughout the United States. A series of online surveys conducted in June 2020 highlights this problem. Out of the surveys' 5,412 respondents, 40.9% of them indicated at least one mental or behavioral health issue, such as signs of anxiety disorder, depressive disorder, or a trauma and stress-related disorder caused in part by the pandemic. Anxiety, in particular, seems to be impacted by the pandemic, with 25.5% of the survey respondents indicating signs of anxiety disorder, a number about 3 times as high as it was in 2019 (Cziesler et al., 2020).

The ways that we protect ourselves from COVID-19 unfortunately also disconnect us from our social networks, a disruption that can have effects on mental health. Data indicates that a greater number of individuals sheltering in place experienced mental health issues related to COVID-19 than individuals who did not shelter in place. COVID-19 has also resulted in loss of jobs or wages for many people. More than half of individuals who suffered from a decline in

income and unemployment indicated mental health issues due to concern about the coronavirus (Panchal et al., 2020). Ultimately, the individuals described above without scleroderma have noticeable mental health effects associated with COVID-19. With this in mind, it is clear that COVID-19 will only add to the mental health concerns already associated with scleroderma.

So what can be done about mental health in the scleroderma community? This is what the Scleroderma Foundation is hoping to address. In collaboration with the Community Technical Assistance Collaborative at the University of Michigan, the Scleroderma Foundation has been collecting and analyzing data on the mental health needs of the scleroderma community and what types of resources they can provide. It is our hope that this new area of focus and programming can help bring attention to and address the mental health issues facing people with scleroderma, especially in light of this challenging time.



(<https://unsplash.com/photos/zRSnKURbKO8>)

Bibliography:

About Chronic Diseases. (2020, October 7). About Chronic Diseases.
<https://www.cdc.gov/chronicdisease/about/index.htm>

Czeisler MÉ , Lane RI, Petrosky E, et al. Mental Health, Substance Use, and Suicidal Ideation During the COVID-19 Pandemic — United States, June 24–30, 2020. MMWR Morb Mortal Wkly Rep 2020;69:1049–1057. DOI: <http://dx.doi.org/10.15585/mmwr.mm6932a1>

Orlandi, M., Lepri, G., Bruni, C., Wang, Y., Bartoloni, A., Zammarchi, L., Cometi, L., Guiducci, S., Matucci-Cerinic, M., & Bellando-Randone, S. (2020). The systemic sclerosis patient in the COVID-19 era: the challenging crossroad between immunosuppression, differential diagnosis and long-term psychological distress. *Clinical rheumatology*, 39(7), 2043–2047.
<https://doi.org/10.1007/s10067-020-05193-2>

Panchal, N., Kamal, R., Orgera, K., Cox, C., Garfield, R., Hamel, L., Muñana, C., & Chidambaram, P. (2020, August 21). *The Implications of COVID-19 for Mental Health and Substance Use*. Kaiser Family Foundation. <https://www.kff.org/coronavirus-covid-19/issue-brief/the-implications-of-covid-19-for-mental-health-and-substance-use/>

Thombs, B. D., Van Lankveld, W., Bassel, M., Baron, M., Buzzo, R., Haslam, S., ... & Kwakkenbos, L. (2010). Psychological health and well-being in systemic sclerosis: State of the science and consensus research agenda. *Arthritis care and research*, 62(8), 1181-1189.

Thombs, B. D., Jewett, L. R., Assassi, S., Baron, M., Bartlett, S. J., Maia, A. C., ... & Hudson, M. (2012). New directions for patient-centred care in scleroderma: the Scleroderma Patient-centred Intervention Network (SPIN). *Clinical and experimental rheumatology*, 30(2 0 71), S23.

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.