Understanding the Mental Health Impact for People Living With Scleroderma Using Real-World Evidence: A Social Media Analysis

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BACKGROUND

Scleroderma, or systemic sclerosis, is a chronic autoimmune condition manifesting in diverse ways, including abnormalities of the skin, digital vasculopathy, and effects on multiple organ systems.[1] Despite ongoing research, there is no cure, and existing treatments primarily aim to limit disease progression and alleviate the wide-ranging symptoms. The burden of managing a spectrum of symptoms,[1] along with the potential visible manifestations of scleroderma on prominent body areas,[2] can impose a significant psychological impact on patients. Comprehensive medical care should address both the physical and emotional aspects of scleroderma. Therefore, this study was designed to explore the relationship between scleroderma and mental health (MH) using personal experiences shared on social media.

METHODS

In this study, we employed a proprietary analytical engine that applied natural language processing (NLP) techniques to health discussions on social media. This analysis incorporated a deep learning model specialized for identifying MH-related posts and comments. In addition, our approach also featured a clinical entity recognition (CER) model to extract clinical terms from social media text. By integrating the findings from both the MH classification and CER model, we were able to construct an MH co-occurrence network. This network served as a tool to elucidate the complex connections between MH and other disease-specific concepts in the context of scleroderma.

RESULTS

FIGURE 1. DATA SOURCE

r/scleroderma

1,533	1,484	7,630
USERS	POSTS	COMMENTS

April 2014 - May 2023
DATE RANGE

Data collected for this study were from a public subreddit, r/scleroderma, which contained 9,114 posts/ comments from 1,533 members from 2014 to 2023.

FIGURE 2. MENTAL HEALTH DISCUSSIONS

The results from the MH classification model showed that 16.4% of the discussions were MH-related.

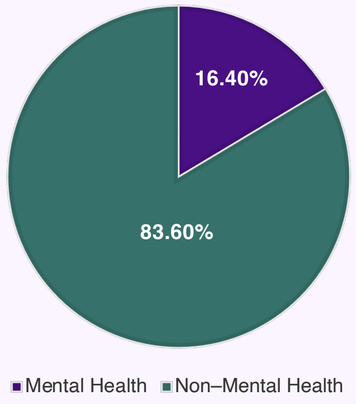
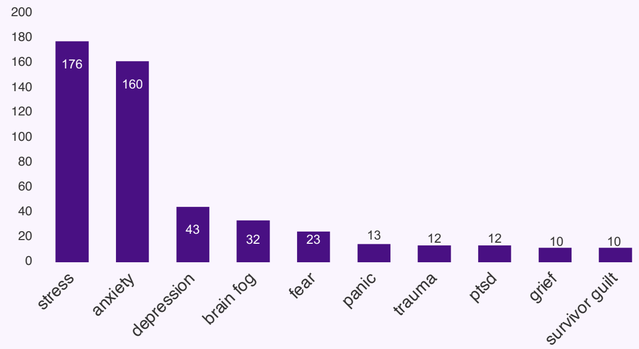
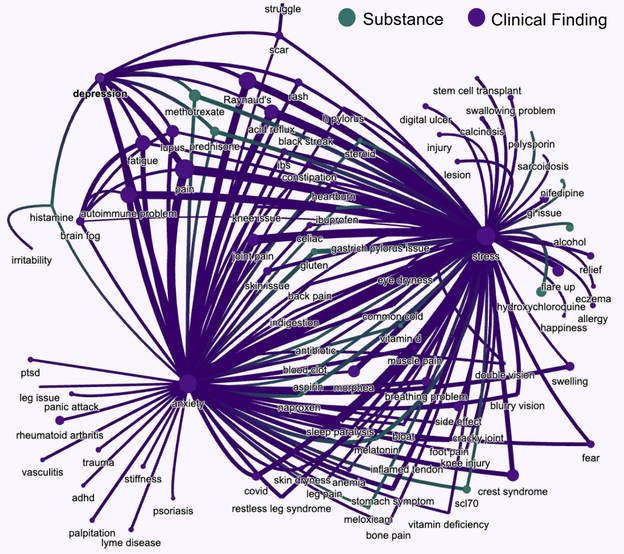


FIGURE 3. TOP 10 MENTAL HEALTH TERMS



The results from the CER model revealed the most prevalent MH issues within this group. ‘stress’, ‘anxiety’, and ‘depression’ emerged as the most common issues. Subsequently, terms such as “brain fog”, “fear”, “panic”, “trauma”, “PTSD”, “grief”, and “survivor guilt” were also mentioned in the conversations.

FIGURE 4. MENTAL HEALTH CO-OCCURRENCE NETWORK



Nodes represent the terms used in the conversations. The color of the nodes corresponds to the types of entities, and the sizes correspond to the frequency of the mentions. Nodes appearing in the same post/comment are connected by edges, with the width representing the frequency of co-mentions. The network indicates that terms such as “autoimmune problem”, “pain”, “Raynaud’s”, “fatigue”, “scar”, and “rash” are associated with “stress”, “anxiety”, and “depression”. Terms regarding pain (e.g., “leg pain”), some gastrointestinal issues (e.g., “ibs”), and other issues, such as “brain fog”, appear to be associated with “stress” and “anxiety” only.

CONCLUSIONS

Our analysis of social media data sheds light on the complex relationship between MH and scleroderma. This study characterized the impact of scleroderma on patients’ mental well-being. The identification of common MH issues such as stress, anxiety, and depression further emphasizes the psychological burden experienced by individuals with scleroderma. Our findings also revealed associations between these MH concerns and various physical symptoms, underscoring the interconnected nature of mental and physical health in scleroderma.

FUTURE DIRECTIONS

Insights from social media data on patients’ experiences accentuate the need for integrated MH support within medical care for scleroderma. Therefore, future efforts should be made toward a holistic approach to scleroderma management that addresses both the physical and psychological aspects of the disease. Inclusion of patient questionnaires assessing physical, social, and emotional functioning within clinical trials can further inform the potential of novel therapeutics in development to address multifaceted burdens of disease. Through these integrated approaches, we can potentially improve the overall well-being and quality of life for individuals living with scleroderma.

DISCLOSURES

The study was funded by Horizon Therapeutics plc. B.L., D.M., and K.D. are employees of and hold stock in Horizon. E.Z., M.F., L.D., J.M., E.R.W., C.D., and M.P. are employees of and hold stock in TREND Community.

Abstract

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Background
Scleroderma, also known as systemic sclerosis, is a rare, chronic, autoimmune disease characterized by the hardening and tightening of skin and fibrosis of internal organs, with wide-ranging systemic manifestations.[1] The pain and organ damage associated with the disease[1] and sometimes-visible nature of scleroderma on prominent areas of the body[2] can have significant psychological impact on patients. Daily impacts of symptoms, the life-threatening nature of the disease, and the realization of limited treatment options and absence of a cure are multifaceted concerns for patients and healthcare providers. The aim of this study was to examine the complex relationship between scleroderma and mental health through an analysis of social media data.

Methods
We used a proprietary analytics engine leveraging natural language processing (NLP) techniques on public conversations about individual experiences with scleroderma. The data source for this study was a public subreddit, r/scleroderma, which contained 9,114 posts/comments from 1,533 members across 9 years (2014-2023). The analytics engine employed a mental health classification model to identify posts/comments about mental health, and a clinical entity recognition (CER) model was built to extract clinical entities from social media text. Using the results from both the mental health classification and CER models, we built a mental health co-occurrence network to understand the relationships between mental health and other disease-specific concepts.

Results
The mental health classification results showed that 16.4% (1,491/9,114 posts/comments) of the conversations were mental health related. The CER revealed the top 3 mental health impacts to be stress, anxiety, and depression, with 176, 160, and 43 mentions, respectively. The mental health co-occurrence network showed that these 3 impacts were all connected with ‘autoimmune problem’, ‘pain’, ‘Raynaud’s’, ‘fatigue’, ‘scar’, ‘rash’, and ‘acid reflux’. Stress and anxiety were also connected to many other clinical findings, such as ‘brain fog’, ‘morphea’, ‘CREST syndrome’, and multiple gastrointestinal issues (eg, ‘irritable bowel syndrome’, ‘celiac’, ‘stomach symptom’). These co-occurrences in patient conversations demonstrated important connections for patients between physical symptoms and mental health burdens.

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Conclusions

Our study conducted social media analysis to investigate the mental health burdens of living with scleroderma. The result highlighted the complexity of the mental health concerns associated with scleroderma and the profound mental health challenges faced by this community. Further work is needed to improve the quality of life for those affected by this disease. This study also revealed the potential of social media data for understanding patient experiences, as well as its value in accelerating patient-centered care for scleroderma, which might be applicable to other chronic diseases.

Acknowledgments

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