

# Advancing Provider Engagement in Assessing Patient Coping for Persons Diagnosed with Scleroderma

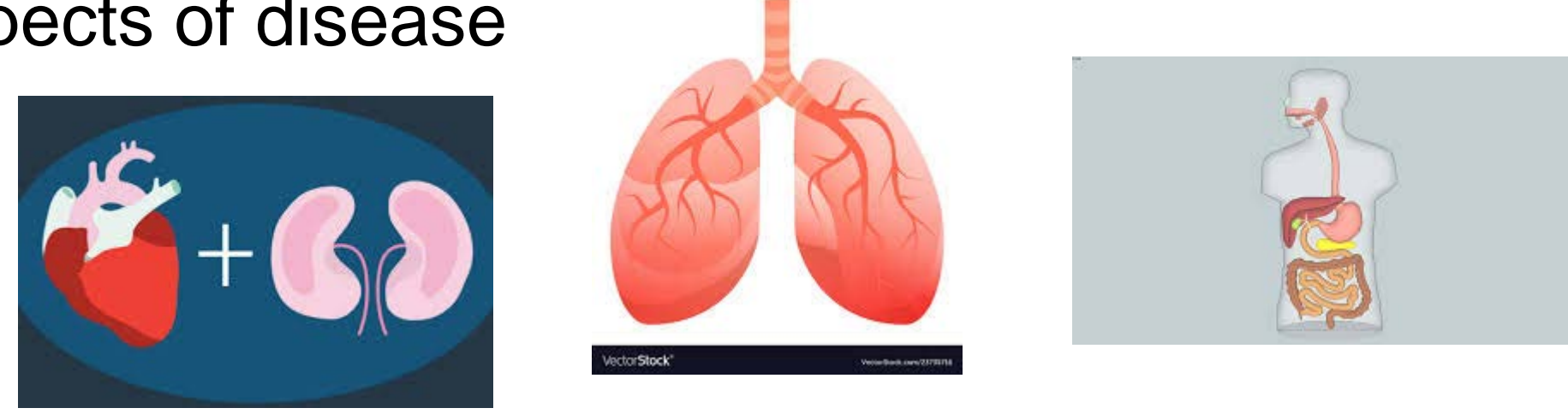
Regina M. Greco, DNP (c) & Sharon Kozachik, PhD, RN, FAAN

Department of Rheumatology, School of Nursing, Johns Hopkins University, Baltimore, MD



JOHNS HOPKINS  
SCHOOL of NURSING

## Introduction

- Scleroderma- rare, autoimmune, multisystem disease lacking patient resources and research on coping.
  - Providers focus on physical manifestations, not the psychosocial aspects of disease
- 
- Psychosocial needs- coping with body image disturbances, depressive symptoms, anxiety, low self-esteem, and medical complications (Leon, et al., 2014)
  - Individually-tailored interventions that address both medical and psychosocial aspects of scleroderma care are needed to provide optimum care (Malcarne et al., 2013).
  - Early detection and treatment of psychosocial problems in scleroderma is pivotal to improved long-term outcomes and quality of life (Leon et al., 2014).

## Background



- The discovery that providers were not asking about coping during clinical visits consistently happened about 3 years ago and a new NP.
- How do persons with scleroderma cope with disabilities and changes?
- When asked, the response was mostly tears, not having reliable resources to help, and a decline in quality of life
- Providers need guidance on coping with scleroderma

## Aims

- To increase provider engagement to assess patient coping
- To increase providers addressing coping during clinical visits

## Methods

- Pre post design quality improvement project conducted at an outpatient scleroderma clinic that is part of an urban academic medical center in the northeast.

## Measures

- Sample 1- 6 scleroderma providers participated in the pre post test intervention
- Sample 2- persons diagnosed with scleroderma with clinical visits pre intervention (9/6/18-11/26/2018), and post intervention (9/9/2019-11/28/2019).
- Questionnaire- Scleroderma and Comfort with Coping (6 Yes/No questions)
- Chart reviews for coping keywords- mood, cope, psychosocial
- Sociodemographic information on Sample 1

Table 1. Sample Demographics	(n=6)
Age mean (median, IQR)	46.33 (41, 16)
Gender (%)	2M: 4F (33.3, 66.7)
Race (%)	3W/2A/1MTOR(50, 33.3, 16.7)
Employment Status (%)	6FT (100)
Level of Education (%)	6MD (100)
Fellowship or training in scleroderma (%)	6Y (100)
Yrs of direct pt care to scleroderma pt mean (median, IQR)	16.67 (12, 20)
Board Certified (%)	6Y (100)
Yrs Board Certified mean (median, IQR)	14.5 (9.5, 17)

IQR indicates Interquartile Range; M, Male; F, female; W, White; A, Asian; MTOR, More than one race; FT, Full Time; MD, Medical Doctor; Y, yes; Yrs, years

## Results

- Aim 1- Wilcoxon signed rank test for pre post survey.
- Median difference- 1.5 ( $p=0.11$ )
- Aim 2- Chi square comparing 2018 and 2019 Epic charts ( $X^2=0.83$ ,  $p=.77$ ) for coping keywords
- 5.7% increase in documented coping keywords from 2018-2019

## Discussion

- Exposure to the coping engagement intervention resulted in an incremental increase (non-significant) in the Scleroderma and Comfort with Coping Assessment scores.
- Likely this was due to a ceiling effect at baseline.
- Existing literature confirms that persons diagnosed with scleroderma face coping-related challenges with lack of resources and lack of provider support for the psychosocial aspect of the disease (Milette et al., 2018).
- By engaging the providers, more persons diagnosed with scleroderma had coping addressed during their clinical visit evidenced by more charts containing the coping keywords following the session.
- Although the provider sample was under-powered to show a statistical effect on the engagement from the intervention, there was a small positive change, which suggests that providers are starting to understand the importance of coping and that it is feasible to address during clinical visits.
- This also means that more persons diagnosed with scleroderma are having their psychosocial needs met.

### Limitations

- Small sample size- 6 providers
- One brief engagement session- adding sessions might have increased engagement
- Urgency meetings were on Fridays- Monday huddles before clinic might have been helpful
- Lacking providers embracing coping- did not measure provider comfort
- Providers were not specifically instructed to document coping- it might have been discussed, but not documented.

### Strengths

- First step to incorporating coping into the standard clinical template in the Epic chart
- Engaged providers to understand the importance of addressing the whole person

## Sustainability

- There are continued efforts on the part of the providers to sustain and improve on coping assessments.
- They are interested in smart phrases to use to document in the chart and in ways to incorporate coping into the standard smart form that currently addresses all the physical manifestations of the disease.
- Pfizer global medical grants just announced a new education request for proposals (RFP) in Rheumatology: Virtual Programs for Rheumatology Education. Pfizer supports quality improvement to improve patient outcomes and especially now, during the COVID-19 global pandemic.
- An application will be submitted to Pfizer for funding for on-line engagement sessions on coping for the providers and for persons diagnosed with scleroderma.

## Acknowledgements

I would like to acknowledge the providers and staff at the Scleroderma Center for all their support during this project. A special thanks to Dr. Fredrick Wigley and Dr. Laura Hummers for their guidance; and Pam Hill for securing the date/time and space for the intervention. I would also like to acknowledge Dr. Jennifer Payne who supported me and helped develop the coping engagement session. Lastly, I would like to acknowledge all the brave persons diagnosed with scleroderma for inspiring me on this journey.

**References:** Leon, L., Abasolo, L., Redondo, M., Perez-Nieto, M. A., Rodriguez-Rodriguez, L., Casado, M. I., Curbelo, R., & Jover, J.A. (2014). Negative affect in systemic sclerosis. *Rheumatology International*, 34(5), 597-604. Malcarne, V. L., Fox, R. S., Mills, S. D., & Gholizadeh, S. (2013). Psychosocial aspects of systemic sclerosis. *Current Opinion in Rheumatology*, 25(6), 707-713. Milette, K., Thombs, B. D., Maiorino, K., Nielson, W. R., Korner, A., & Pelaez, S. (2018). Challenges and strategies for coping with scleroderma: Implications for a scleroderma-specific self-management program. *Disability and Rehabilitation*, 1-10