

UNDERSTANDING THE DIAGNOSTIC AND PSYCHOSOCIAL EXPERIENCE OF DERMATOMYOSITIS IN PATIENTS OF COLOR: A SURVEY-BASED STUDY

Kyanna W. Johnson, Mallory Von Lotten, Lauren Van Duyn Graham, Lynn Wilson, Elisa Glass
University of Alabama at Birmingham Heersink School of Medicine
Myositis Support & Understanding (MSU), Lincoln, DE

Abstract

PURPOSE: Dermatomyositis (DM) is a rare inflammatory myopathy affecting skin and muscle that is often underrecognized in patients of color due to limited representation in clinical educational materials. Patients of color may experience diagnostic delays or inadequate care due to limited provider familiarity with skin tone variation. Understanding these experiences is essential to inform medical education and improve clinical recognition.

METHODS: An anonymous online survey was distributed through the Myositis Support and Understanding (MSU) Facebook community. Adults (≥18 years) with a self-reported DM diagnosis completed a Qualtrics survey.

RESULTS: Among 95 respondents, 49% reported clinicians did not recognize symptoms on their skin tone, and 77% needed to self-advocate for testing or referral. Thirty percent felt dermatology training inadequately addresses diagnosis in patients of color, with the following disparities noted (52% vs 23%). Free-text themes described multi-year diagnostic delays, repeated misdiagnoses, and mistrust.

CONCLUSION: These findings demonstrate persistent educational and diagnostic gaps in DM recognition across skin tones and support the need for the urgent expansion of skin-of-color representation in training to improve diagnostic accuracy, reduce disparities, and ensure timely care.

Introduction

- DM presents with proximal **muscle weakness and variable and distinctive skin manifestations** (1).
- Common features include **heliotrope rash, Gottron papules (Figures 4, 5, 6), shawl and V signs (Figure 3), nailfold changes (Figure 6), along with extra-muscular involvement** such as interstitial lung disease, arthritis, dysphagia, and cardiac complications.
- Cutaneous findings may appear more subtle in darker skin tones, requiring attention to lesion distribution patterns, rather than erythema alone to avoid delaying diagnosis** (2).
- Early recognition is critical in primary care, as symptoms often mimic common conditions and **delayed diagnosis may postpone malignancy screening and coordinated treatment** (2).
- Educational gaps exist: >70% of dermatology images in a systematic review represented the lightest skin tones, **while <2% represented the darkest skin tones** (3).
- Because skin disease presentation varies across skin tones, **limited representation may impair diagnostic accuracy and contribute to diagnostic delays in patients of color** (4).
- This cross-sectional study evaluates diagnostic experiences, clinical recognition, access to care, and the psychosocial impact in patients with DM.

Methods

- Cross-sectional, anonymous survey
- Distributed via Myositis Support and Understanding (MSU) Facebook Community
- August- October 2025, Adults ≥18 with self-reported DM
- Qualtrics survey assessed diagnosis, provider recognition, access to care, and psychosocial impact
- Analysis: quantitative + qualitative thematic analysis

Results

Characteristic	n (%)
Age (years)	
18–24	2 (2%)
25–34	15 (16%)
35–44	22 (23%)
45–54	26 (27%)
55–64	21 (22%)
≥65	9 (9%)
Sex/Gender	
Female	86 (91%)
Male	9 (9%)
Race/Ethnicity	
White	67 (71%)
Black or African American	11 (12%)
Hispanic or Latino	9 (9%)
Asian	2 (2%)
Other / Multiracial*	6 (6%)
Patients of color	26 (27%)

Table 1. Demographic Characteristics of Survey Respondents (N = 95)

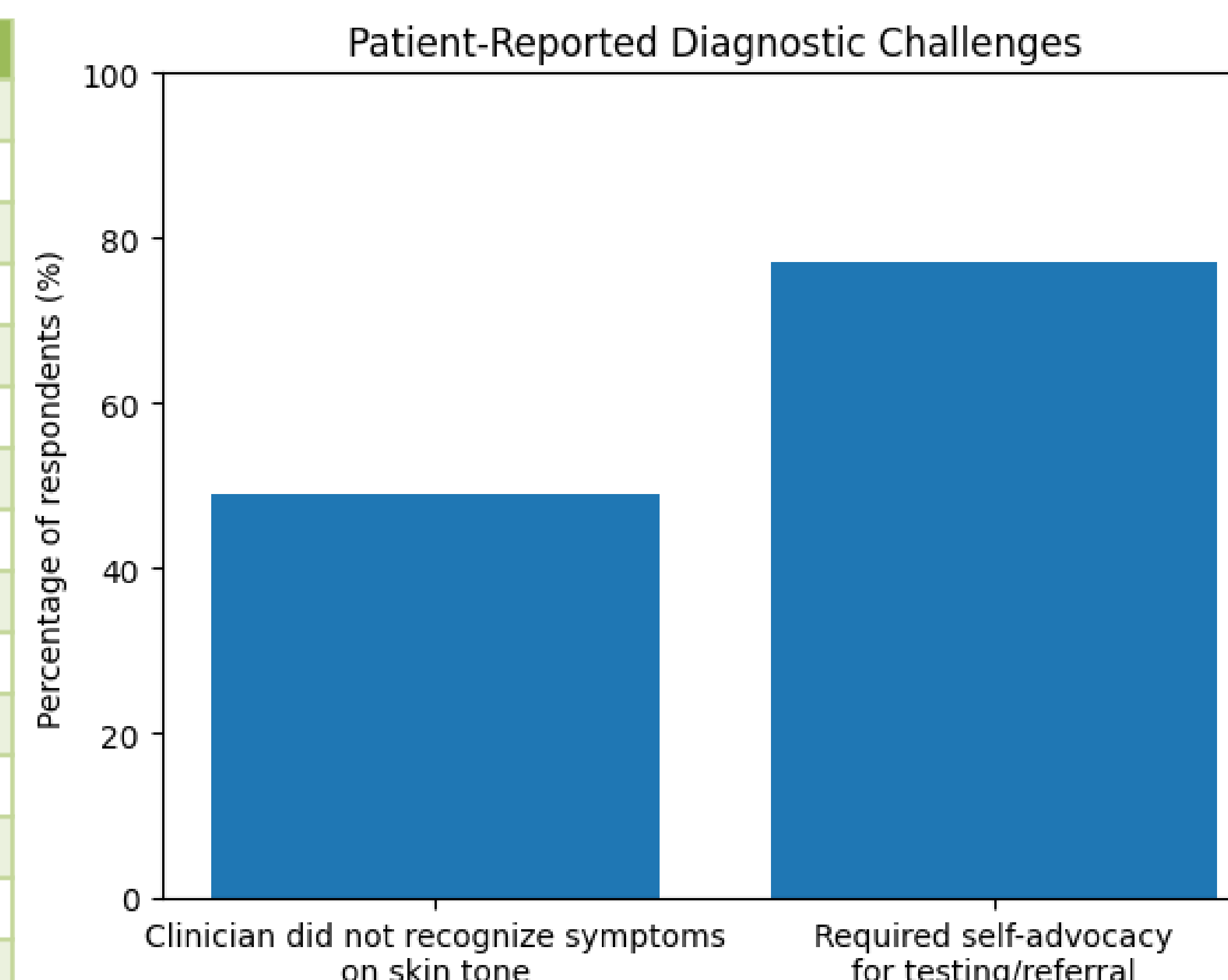


Figure 1. Patient-reported diagnostic challenges in DM

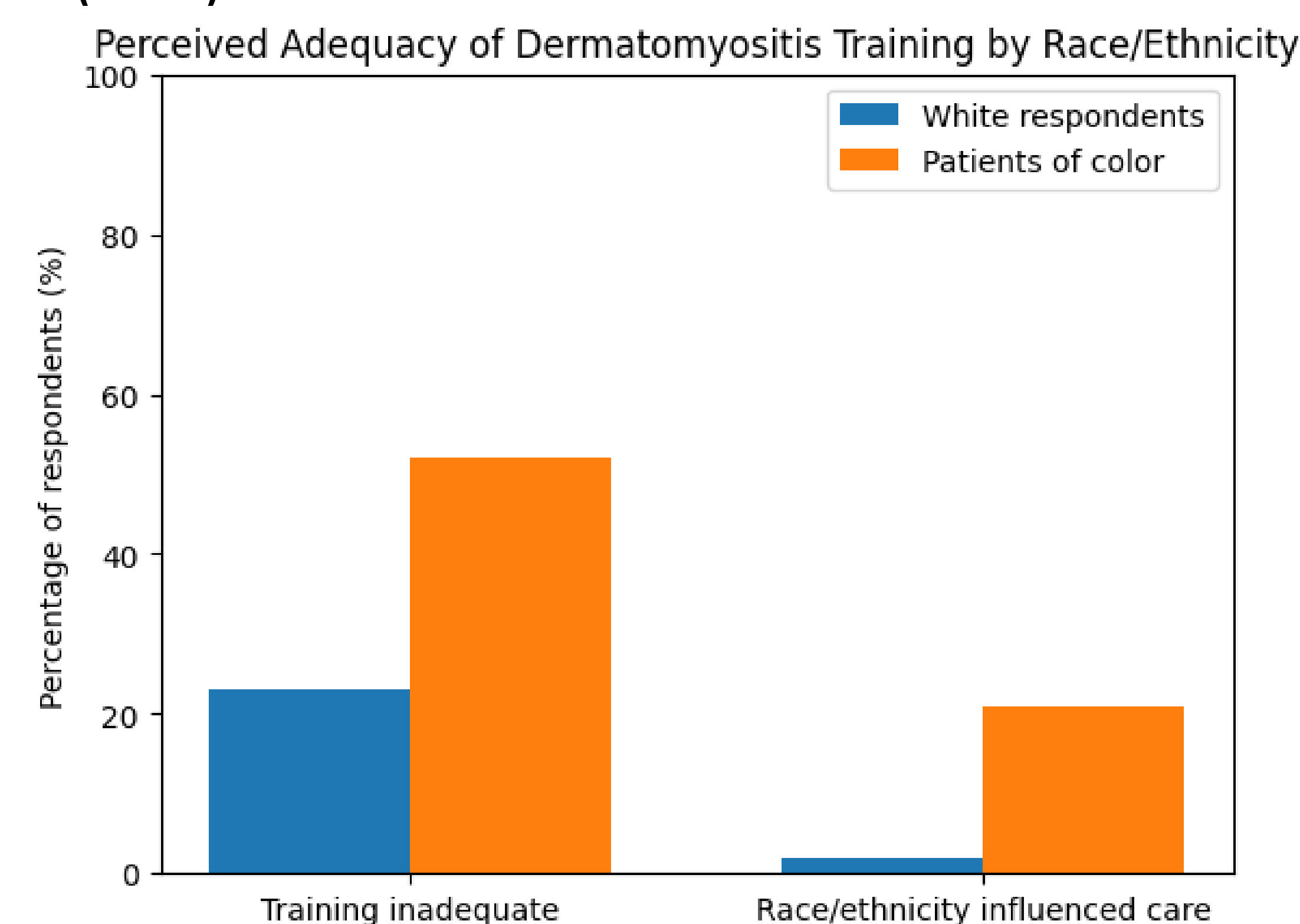


Figure 2. Perceived adequacy of DM training by race/ethnicity

Improving DM care requires better recognition across skin tones and training that emphasizes early diagnosis, equitable representation, and patient-centered communication.

Results cont.

- N=95, 27%** patients of color
- 49%** reported that a **clinician did NOT recognize symptoms on skin tone**
- 77%** needed to **self-advocate** for testing or referral
- 30%** felt that current dermatology training inadequately addresses the diagnosis of DM in patients of color
- 52% vs 23%:** perceived training gaps (patients of color vs White patients)
- Cutaneous findings often present early, but are not initially recognized**
- Respondents of color more frequently reported believing that their racial or ethnic identity influenced the care they received (**21% vs 2% among White respondents**).

Psychosocial Impact and Patient Perspectives

- Frustration, mistrust, and emotional distress**
- Multi-year delays and misdiagnoses**



Figure 3. Classic V Sign Rash



Figure 4. Gottron Papules/Sign



Figure 5. Gottron Papules/Sign on MCP Joints on Darker Skin



Figure 6. Gottron Papules/Sign With Close-Up Image Showing Cuticular Hypertrophy and Periungual Capillary Dilation

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