Characteristics, treatments, and outcomes of patients with dermatomyositis from two large, nationwide US cohorts

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Background/Purpose

- Studies of dermatomyositis (DM) are frequently limited to single center cohorts at academic centers.
- Goal: Describe characteristics, treatments, and outcomes of patients with incident DM in two large, nationally representative US cohorts

Methods

- Retrospective study of two inception DM cohorts using 1) Augmented commercial claims (e.g. with mortality data) derived from Komodo Healthmap data 1/1/2016 to 12/31/2023 and 2) Electronic health record (EHR) data 10/1/2014 to 9/30/2023 from the Excellence Network in RheumatoloGY (ENRGY), a community rheumatology practice-based research network (PBRN) of >700 rheumatology providers.
- DM based on one inpatient or two outpatient DM ICD-10 codes (M33.1* or M33.9*). The second outpatient diagnosis code defined the index date.
- Excluded if other myositis diagnoses or immunomodulatory therapy except hydroxychloroquine prior to first DM diagnosis or malignancy prior to index.
- Patient characteristics, treatments, and healthcare utilization assessed 18 months before and 12 months after index in claimsand 12 months before and after index in EHR data; time-to-event analyses assessed incidence of outcomes (e.g., hospitalization, malignancy) after index in claims data.

Results

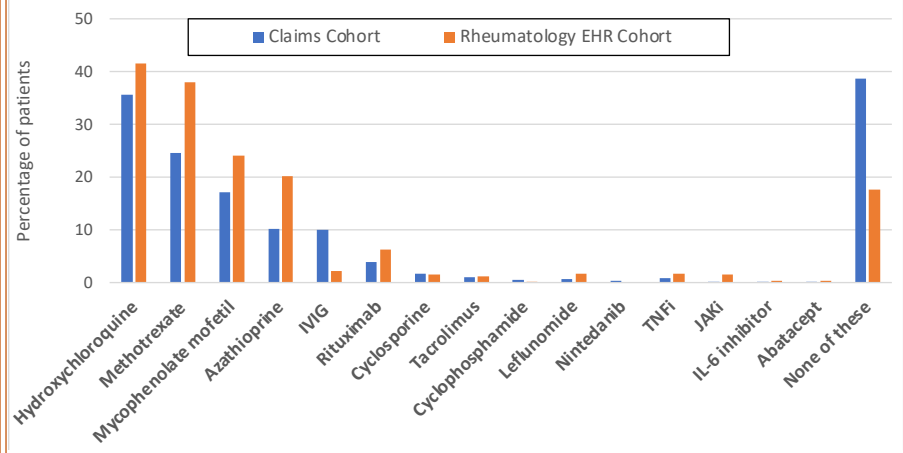
Table 1: Characteristics of two incident dermatomyositis cohorts

	Commercial health plan cohort N = 2,475	Rheumatology EHR cohort N = 1,196
Age, years, mean (SD)	53.4 (15.5)	56.2 (15.7)
Female	1,852 (74.8)	932 (77.9)
Race/ethnicity		
White, non-Hispanic	1,292 (52.2)	703 (58.8)
Black or African American, non-Hispanic	234 (9.5)	96 (8.0)
Hispanic or Latino	244 (9.9)	112 (9.4)
Asian or Pacific Islander	96 (3.9)	26 (2.2)
Other/Unknown	609 (24.6)	259 (21.7)
Geographic region		
Midwest	566 (22.9)	141 (11.8)
Northeast	617 (24.9)	135 (11.3)
West	345 (13.9)	794 (66.4)
South	946 (38.2)	126 (10.5)
Rheumatology provider visit*	977 (50.4)	1,196 (100.0)
Select Comorbidities		
Diabetes mellitus	421 (17.0)	198 (16.6)
Hyperlipidemia	844 (34.1)	335 (28.0)
Ischemic heart disease	228 (9.2)	12 (1.0)
Osteoporosis	121 (4.9)	150 (12.5)
ILD diagnosis codes	212 (10.9)	60 (5.0)
Glucocorticoids	1,332 (68.7)	883 (73.8)
Glucocorticoid initial dose		
<10mg/day	441 (33.1)	50 (5.8)
10-<20mg/day	411 (30.9)	304 (35.3)
≥20mg/day	480 (36.0)	508 (58.9)
Unknown	0	21
Cumulative GC dose, mean (SD)	1,407 (1,981)	Not measured
Opioids	773 (39.9)	259 (21.7)
NSAIDs	685 (35.3)	492 (41.2)

N (%) except as indicated. Comorbidities assessed in the 18 months prior to the index date in the claims cohort and the 12 months before and after the index date in the EHR cohort. ILD (set of validated diagnoses) and medication use were assessed 18 months before and 12 months after index in claims and 12 months before and after index in the EHR cohort. Cumulative GC dose reported among users.

EHR = electronic health record; ILD = interstitial lung disease; SD = standard deviation; GC = glucocorticoid; NSAIDs= nonsteroidal anti-inflammatory drugs.

Figure 1: Immunomodulatory therapy use in the Claims and EHR cohorts



Immunomodulatory therapy use 18 months before and 12 months after index in the claims cohort (prescription fills and infusions), and 12 months before and after index in the EHR cohort. EHR = electronic health record; IVIG = intravenous immunoglobulin; TNFi = tumor necrosis factor inhibitor; JAKi = Janus kinase inhibitor

Table 2: Rates of selected events of interest during follow-up after the index date in patients in the Claims cohort

Event Type (all events)	Number of Events	Person-years	Incidence rate per 1000 patient-years (95% CI)
Incident all-cause hospitalization	176	5,578	31.6 (27.1, 36.5)
Incident malignancy	87	5,693	15.3 (12.3, 18.8)
Incident ILD	33	5,189	6.4 (4.5, 8.8)
Gastrostomy tube placement	17	5,828	2.9 (1.8, 4.6)
Incident myocarditis	12	5,802	2.1 (1.1, 3.5)
Hospitalized myocarditis	5	5,822	0.9 (0.3, 1.9)

CI = confidence interval; ILD = interstitial lung disease.

- We identified 2475 incident DM patients (claims cohort) and 1,196 patients (EHR cohort) [**Table 1**], excluding 12.7% and 4.3% for malignancy.
- Most frequent myositis specific antibodies (EHR cohort): TIF-1γ (41 positive/240 tested, 17%), NXP-2 (39/336, 12%), and Jo-1 (31/620, 5%).
- Among 998 with any laboratory results available, 745 (74.6%) had a positive myositis-specific or -associated antibody positivity.
- Glucocorticoid use was common, 68.7% and 73.8% in the two cohorts, initial doses most often > 20mg/day.
- Immunomodulatory use varied – hydroxychloroquine, methotrexate, mycophenolate most commonly used [**Figure 1**].
- During follow-up, high incidence of hospitalization (31.6/1000 person-years) and malignancy (15.3/1000); lower for other outcomes [**Table 2**].

Conclusions

- Augmented claims and rheumatology electronic health record data can be used to assess comorbidities, treatments, hospitalizations, and other outcomes in real-world dermatomyositis cohorts.
- High glucocorticoid burden and highly variable treatment approaches highlight the need for more effective therapies for dermatomyositis.

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