Treatment Satisfaction, Disease Control, and Patient-Defined Treatment Goals Across Myositis Subtypes: An Interim Analysis of a Cross-Sectional Patient-Reported Outcomes Survey

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PURPOSE

The different idiopathic inflammatory myopathies, including dermatomyositis (DM), polymyositis (PM), immune-mediated necrotizing myopathy (IMNM), and antisynthetase syndrome (ASyS), have distinct symptom profiles and disease trajectories, yet subtype-specific differences in treatment outcomes and patient priorities remain poorly characterized. We conducted a patient survey to assess treatment satisfaction and subtype-specific patient-defined treatment goals, with a goal of identifying unmet needs and informing patient-centered approaches to care.

RESULTS

Of 97 respondents, 93 had received treatment and were included in the analysis (Mean age = 49.2 years; 74 Women, 19 Men; 46 DM, 20 PM, 14 IMNM, 7 ASyS, 6 Unknown). Respondents had tried a mean of 3.6 treatments, but only 32% of participants reported being very satisfied with their current treatment regimen(Figure 2), Mean treatment satisfaction was higher in DM vs other subtypes (4.13 vs 3.66 out of 5, Mann-Whitney p = 0.041) (Figure 2). Additionally, 38% reported inadequate disease control (not very well or not at all controlled), with no significant difference across groups. The top treatment goals were Improved Mobility or Ability to Exercise (38.7%), Reduce Fatigue or Increase Energy (35.5%), and Maintain Independence in Daily Life (33.3%). People with DM more frequently prioritized reduction of pain or discomfort (34.8% vs. 17.0%; p=0.06) and improvement of emotional and physical well-being (28.3% vs. 14.9%; Fisher's exact p=0.13), while patients with other subtypes more frequently prioritized improvement of mobility and ability to exercise (53.2% vs. 23.9%; p=0.006) (Figure 3).

Figure 2: Differences in Treatment Satisfaction between Dermatomyositis and Other Subtypes

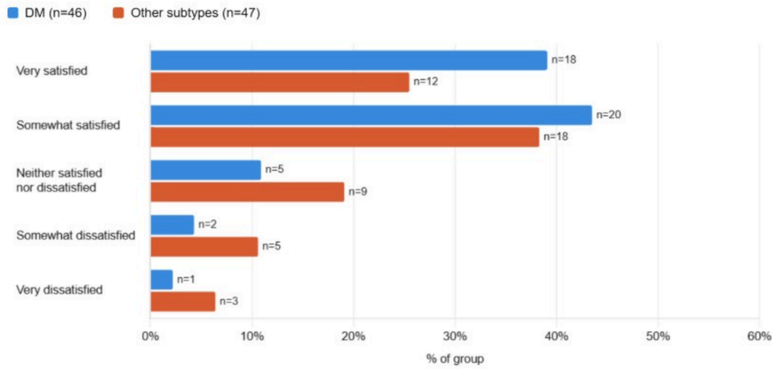


Figure 2. Overall treatment satisfaction for dermatomyositis (DM, n=46) vs. other myositis subtypes (n=47). Chi-square p=0.317; Mann-Whitney p=0.041.

METHODS

This interim analysis presents data from a cross-sectional, 51-item survey distributed to individuals with a confirmed myositis diagnosis (April 22 to May 28, 2026). Participants were recruited through multiple channels, including the PatientSpot registry, the CreakyJoints online community, and in-person outreach, to ensure broad reach across the myositis patient population. Survey domains included Diagnosis, Treatment, Daily Life and Coping, and Looking Ahead. Analyses reported here are restricted to the Treatment domain. Descriptive statistics characterized the full sample. Between-group comparisons were conducted using chi-square, Mann-Whitney U, and Fisher's exact tests as appropriate, comparing those with DM to other subtypes given the smaller number of participants with each of the other subtypes.

Figure 3: Treatment Goal Differences between Dermatomyositis and Other Subtypes

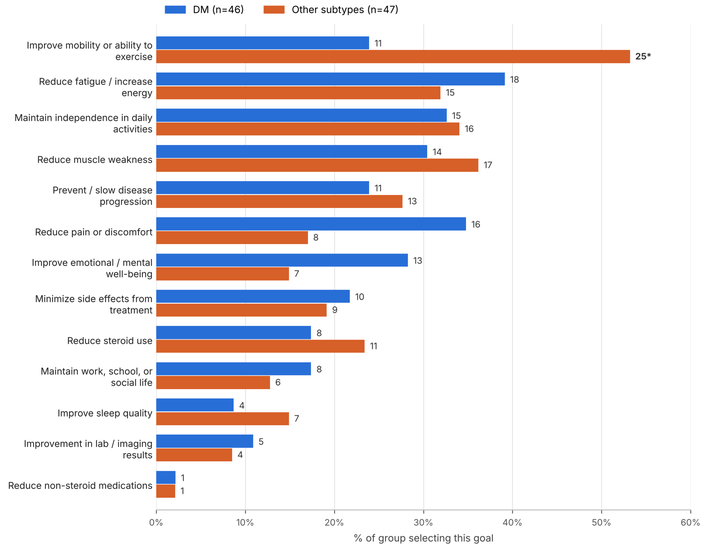


Figure 3. Treatment goals selected by dermatomyositis (DM, n=46) vs. other myositis subtypes (n=47), sorted by most to least commonly selected overall. Bar length shows the percentage of each group selecting the goal; numbers at the end of each bar are the number of respondents (n). Up to 3 goals permitted per respondent. *p<0.05 (Fisher's exact, p=0.006).

CONCLUSIONS

This interim analysis reveals a critical unmet need, with fewer than one third of people with myositis reporting being very satisfied with their current regimen, and more than a third reporting inadequate disease control. Improving mobility, strength, fatigue, and pain emerged as top patient priorities, with some important differences across disease subgroups, underscoring the need to target treatment goals to specific patient priorities. Complete data from the full study cohort will be presented at the congress, providing a more comprehensive characterization of treatment experience and unmet needs across myositis subtypes.

Figure 1: Prescription Treatments Used and Number Tried per Patient

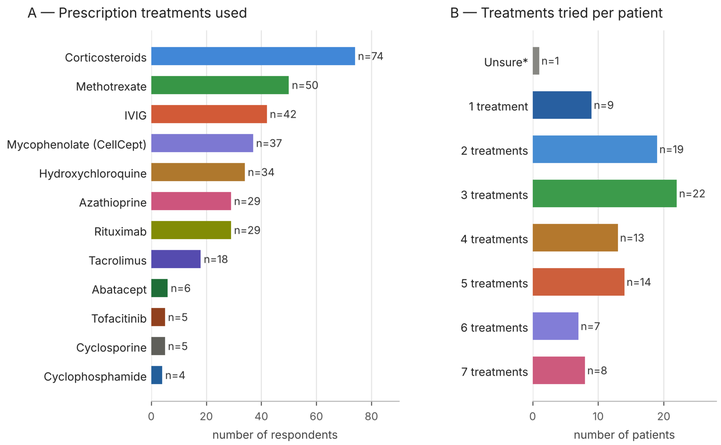


Figure 1. (A) Prescription treatments ever used by participants with myositis (n=93); multiple selections permitted; values show number of respondents. Panel A totals exceed 93 due to multi-select design. (B) Number of prescription treatments ever tried per patient (n=93); mean 3.6, median 3.0, range 1–7 among the 92 participants who named at least one treatment. *One participant reported receiving treatment but was unsure which prescription medications they had used.