Risk factors for delayed diagnosis of myositis: A cross-sectional study of 470 patients

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INTRODUCTION

Myositis can be difficult to diagnosis leading to delayed diagnosis and increased morbidity. The various forms of myositis have a low prevalence and are categorized as rare diseases (1). Additionally, the lack of familiarity that clinicians have to these disorders contribute to possible delays in diagnosis. Myositis has a broad range of clinical features and lacks conclusive diagnostic testing, which may also contributor to delayed diagnosis (2-4).

With the support of Myositis Support and Understanding, a patient-led advocacy group, we sought to understand the factors that may contribute to delays in diagnosis.

OBJECTIVES

We aimed to investigate the risk factors for delayed diagnosis. Specifically, we were interested in understanding how proximity to specialists, insurance status, and income contribute to time to diagnosis.

METHODS

Data source:

An anonymous survey was created to assess the risk factors for diagnostic delay in myositis. This survey was subsequently distributed via RedCAP to members of MSU (Myositis Support and Understanding) worldwide. Over the course of 4 weeks, 470 participants responded with data captured in RedCAP in a de-identified manner. Participants aged 18 years and older with a self-reported diagnosis of IIM (Dermatomyositis, Inclusion Body Myositis, Necrotizing Myopathy, Polymyositis, Overlap/MCTD) were included in the survey. Participants who described other forms of IIM were excluded.

Survey:

Demographic and diagnostic information collected from participants included age, sex, specific myositis diagnosis, and time elapsed since diagnosis. Participants were asked about factors around their care including distance to a myositis specialist, the number of providers seen prior to diagnosis, insurance status, and income.

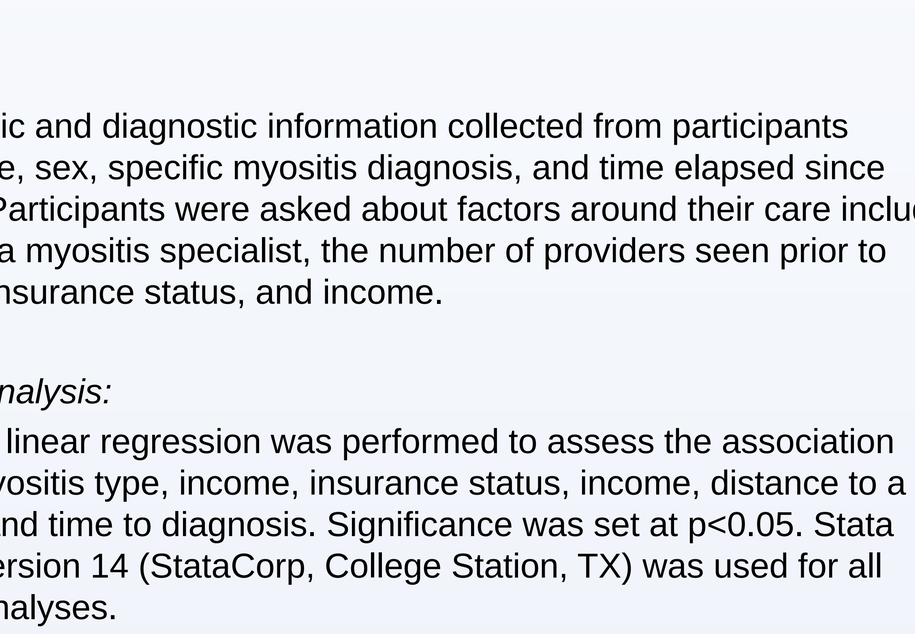
Statistical analysis:

Multivariate linear regression was performed to assess the association between myositis type, income, insurance status, income, distance to a specialist, and time to diagnosis. Significance was set at $p<0.05$. Stata software, version 14 (StataCorp, College Station, TX) was used for all statistical analyses.

RESULTS

Survey demographics:

A majority of survey participants were women (71.3%, n=333) and were white (87.2%, n=410). Inclusion body myositis (41.1%, n=193) and dermatomyositis (27.2%, n=128) were the two most commonly reported myositis subtype diagnoses. The majority of participants were between the ages of 50-79.



RESULTS

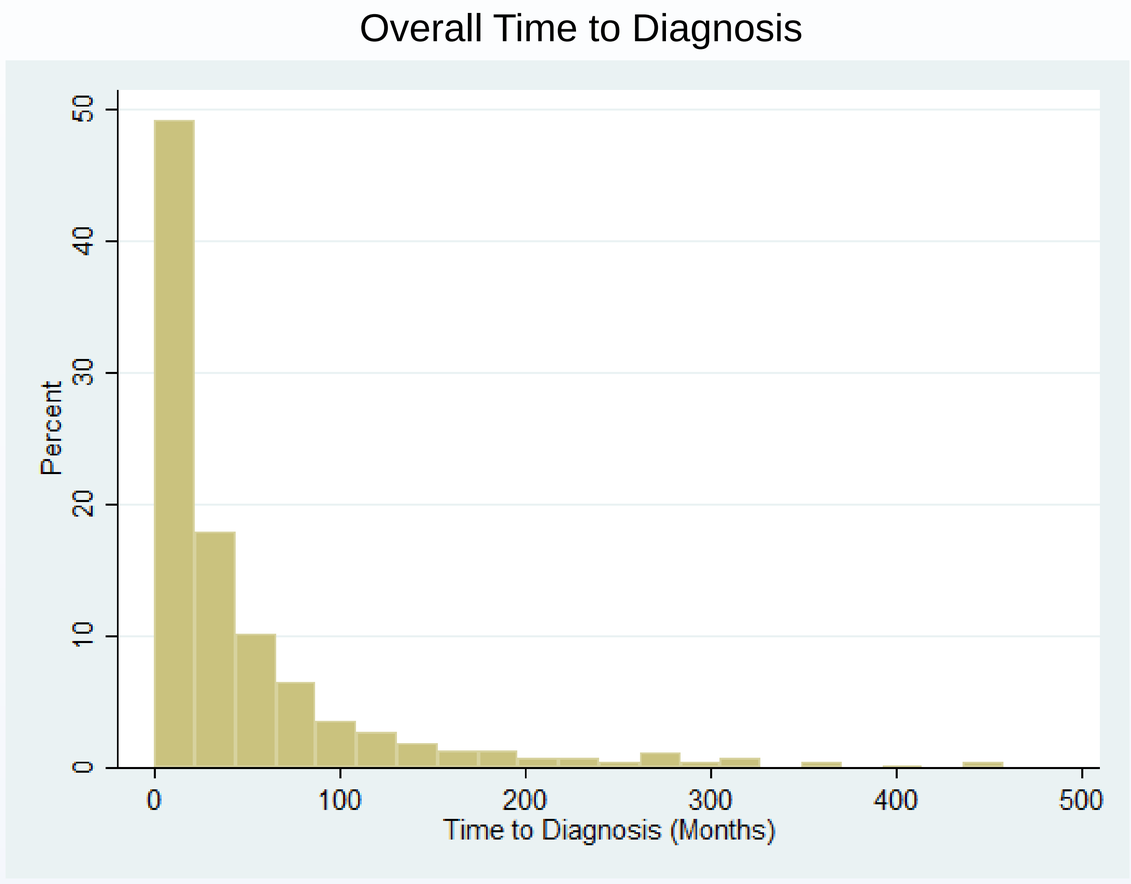
Time to diagnosis:

The average time to diagnosis was 28.1 months (range: 0-120 months). 33.8% of patients had to travel >50 miles to a center of excellence and 64% of patients saw >2 providers before a diagnosis was made.

Using multivariable linear regression, variables associated with longer time to diagnosis were:

1. having inclusion body myositis (coefficient=54, $p<0.001$),
2. seeing >2 providers (coefficient=32, $p<0.001$),
3. being uninsured versus (coefficient=52, $p=0.003$),
4. having income <$20,000/year (coefficient 42, $p=0.005$).

Women did not have a longer time to diagnosis then men (coefficient=13 months, $p=0.093$).



CONCLUSIONS

Based on this analysis, time to diagnosis can be minimized by early referral to myositis specialists, especially when there is concern for inclusion body myositis. To obtain faster diagnosis, uninsured and poorer patients are likely to require social support.

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