


BRIEF REPORT

Access to Care and Diagnostic Delays in Juvenile Dermatomyositis: Results From the Childhood Arthritis and Rheumatology Research Alliance Legacy Registry

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Objective. To determine factors associated with diagnostic delays and outcomes in juvenile dermatomyositis (JDM) in the Childhood Arthritis and Rheumatology Research Alliance Legacy Registry (CLR).

Methods. This was a cross-sectional study of subjects aged 0 to 17 years with JDM enrolled to the CLR from 2010 to 2015. Access to care was measured by calculating the distance from the subject zip code of residence to the treating pediatric rheumatology center and determining the state density of pediatric rheumatologists based on the 2015 American College of Rheumatology Workforce Study. Delay was categorized as early (<30 days), typical (1-3 months), moderate (3-12 months), and severe (>12 months). Ordered generalized additive models were used to determine the association between these measures and diagnostic delays.

Results. The median time to diagnosis was 3.1 months; 37.2% of patients experienced moderate delays, and 14.6% experienced severe delays. In a univariate analysis, younger age of disease onset and male sex were associated with delays. Using a generalized additive model accounting for age, sex, race, and ethnicity, increasing distance from treating pediatric rheumatologist and younger age at disease onset were associated with diagnostic delay. There was no association between the state density of rheumatologists and diagnostic delays in this model.

Conclusion. In the CLR, we found moderate to severe diagnostic delays in the majority of subjects with JDM. Our data suggest that access to care, measured as the distance traveled to treating rheumatologist, is an important factor associated with delays in care but also highlight age as a contributing factor, suggesting that JDM may be less recognizable in young children.

INTRODUCTION

Juvenile dermatomyositis (JDM) is a rare pediatric autoimmune disorder characterized by muscle inflammation that is distinguished from other juvenile idiopathic inflammatory myopathies by distinctive rashes in stereotypical distributions. Untreated, JDM can cause long-term damage and functional decline (1,2). Past studies have shown that delayed diagnosis, race, and socioeconomic factors are associated with disease morbidity, including the development of calcinosis (3,4), and it has been shown that early,

aggressive treatment leads to better outcomes (5). A recent study in childhood-onset systemic lupus erythematosus (SLE) identified significant delays to first pediatric rheumatology visit and found that severe delays were associated with younger age of onset and low income (6), but this has not been explored in patients with JDM.

Currently there are fewer than 400 board-certified pediatric rheumatologists (PRs) practicing in the United States. Analyses of data from the most recent 2017 American Board of Pediatrics Workforce Data Book found that nine states have no PRs (7). Limited access to a PR and rare disease manifestations are

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SIGNIFICANCE & INNOVATIONS

- The majority of subjects with juvenile dermatomyositis enrolled to the Childhood Arthritis and Rheumatology Research Alliance Legacy Registry between 2010 and 2015 experienced diagnostic delays of more than 3 months, with 14% having delays of more than 1 year.
- Delays were associated with increasing distance traveled to treating pediatric rheumatologist and younger age at disease onset, highlighting factors that impede timely diagnosis.
- This study emphasizes the need to expand access to pediatric rheumatology care through expanding both the size and reach of the pediatric rheumatology workforce as well as the need to enhance education of primary care clinicians regarding the diverse presentations of juvenile dermatomyositis.

associated with diagnostic delays in childhood rheumatic diseases (8). A regional survey of primary care pediatricians in Minnesota, North Dakota, and South Dakota regarding referral practices to PRs suggested that the distance to nearest PR in addition to perceived wait time influenced their referral practices and may lead to late referral/diagnosis (9).

In this study, we investigated whether distance from the treating rheumatology center and state density of PRs are associated with diagnostic delays in subjects with JDM enrolled to the Childhood Arthritis and Rheumatology Research Alliance (CARRA) Legacy Registry (CLR). Our goal was to learn which factors might be associated with diagnostic delays in JDM to inform future research, raise awareness, and motivate initiatives to address these factors in order to improve diagnosis and outcomes in children with JDM.

PATIENTS AND METHODS

Patients. This was a cross-sectional study of patients meeting definite or probable diagnostic criteria for JDM ($n = 668$) enrolled in the CLR—the first iteration of a registry of children and young adults with rheumatic disease designed to allow larger-scale research on rare pediatric conditions—from pediatric rheumatology centers across the United States between 2010 and 2015. This was a convenience cohort, and subjects could be enrolled at any point in the disease course. Overall, these subjects trended toward milder disease (10), with the majority of patients having no weakness, and they had a median disease duration of 3.8 years (interquartile range [IQR] 1.6–6.7 years) (10). Those with incomplete data for the variables “date of symptom onset,” “date of diagnosis,” and “zip code” were excluded, resulting in a data set of 522 individuals.

Methods. The driving distance in miles from the subject zip code centroid to the treating rheumatology center zip code centroid as defined by Google Maps was calculated using the R package “gmapsdistance”. To identify outliers, we first

imposed a cutoff of less than 250 miles driving distance on the basis of prior work analyzing the effect of distance in other subspecialties (11,12). Knowing that some patients may truly travel more than 403.2 kilometers (i.e., 250 miles) to pediatric rheumatology centers, we then individually examined these entries for inclusion using the following logic: patients traveling more than 250 miles were included if they were traveling to an institution within their own state, to a bordering state, or to a known encatchment area (ie, Idaho is an encatchment area for both Seattle and Colorado centers). The remaining observations not meeting this criteria ($n = 20$) were deemed to be outliers and were removed from the analysis on the assumption that these were patients traveling by air for second opinions or data entry errors. The density of PRs per state was obtained from the 2015 American College of Rheumatology (ACR) Workforce Study (13) and were calculated by dividing the state population of children by the number of practicing PRs within that state. Additional covariates were obtained from the CLR and included age, sex, race, and household income. Race was defined as white, Black, and other minority race because of a low percentage of nonwhite subjects in the registry. Subjects classified as other minority race identified as Asian, American Indian or Alaskan Native, Native Hawaiian or Pacific Islander, or multiracial/other. Hispanic ethnicity was assessed as a separate variable. Our primary outcome was diagnostic delay, which was defined as early (<30 days), typical (1–3 months), moderate delay (3–12 months), and severe delay (>12 months). These categories were chosen on the basis of existing literature evaluating delays in pediatric lupus (6). The first day of the month was used to calculate the time to diagnosis for patients who reported only the month and year of symptom onset.

Statistical analysis. Subjects were stratified by delay category and comparisons were made using χ^2 tests for categorical variables and Kruskal-Wallis tests for continuous variables, which all demonstrated a non-normal distribution. To model the relationship between the primary predictors (distance to a PR and density of PRs) and diagnostic delay, we used an ordered generalized additive model (GAM). GAMs allow for the addition of smoothed predictors that may not be linearly related to the outcome and are useful for evaluating data with a geospatial element. In addition to the P value, we also assessed predictor significance using the Akaike information criterion (AIC), an estimator of the quality of the model that also penalizes the inclusion of additional terms, with and without each predictor. Predictors that improved (decreased) the AIC by two or more points were considered to be important in the model. To test for residual spatial autocorrelation, Moran’s I test was run on the residuals from the model. We additionally evaluated for correlation between distance traveled and density of PRs using the Pearson correlation coefficient.

RESULTS

Patient characteristics. A total of 494 patients were included after applying exclusion criteria for missing variables and removing 18 outliers. Overall patient characteristics are displayed in Supplementary Table 1, and the geographic locations of these observations are displayed on a US map in Supplementary Figure 1. Median age at disease onset was 5 years (IQR 3-9), and 72.0% of subjects were female. The majority (78.6%) of subjects identified as white, whereas 11.8% identified as Black, and 9.6% identified as another minority. Additionally, 14.6% reported Hispanic ethnicity. The median disease duration was 1.9 years (IQR 0.5-4.4 years). The median time to diagnosis was 3.1 months, with the highest percentage of patients, 37.2%, presenting with moderate diagnostic delays of 3 to 12 months and 14.6% of patients presenting with severe delays of more than 1 year. Early diagnosis was seen in 16.4% of subjects, and typical diagnosis was made in 31.8% of subjects. The median distance subjects traveled to the treating pediatric rheumatology center was 42 miles (IQR 18-113). The median density of children per PR was approximately 250 000 (IQR 147 000-399 000).

Factors associated with diagnostic delay. Stratified by delay, factors associated with diagnostic delay in a univariate analysis included younger age at disease onset and male sex (see Table 1). In a GAM (reduced to a total number of 480 subjects because of incomplete data for 14 observations), which included a smoothed effect of distance to treating PR, smoothed density of PRs, age, sex, race, and Hispanic ethnicity, distance to treating PR ($P = 0.02$) and younger age at disease onset ($P = 0.01$) were significantly associated with diagnostic delays (see Table 2). The odds ratios in this model represent the odds of being in a higher delay category (ie, increasing by one or more delay category) for every unit increase in the covariate. The relationship between distance to treating PR and delay is graphically displayed in Figure 1,

which demonstrates increasing log odds of increasing one delay category with increasing distance traveled. However, the confidence of this estimate greatly decreases for observations of more than 400 miles, as there are very few observations in this range. This model performs well at predicting subjects in the typical diagnosis and moderate delay categories but performs less well at predicting those in the early diagnosis and severe delay categories, indicating some unmeasured variables may be more important in predicting time to diagnosis for these two categories.

Younger age at disease onset was associated with diagnostic delay with a reduction in the odds of being in a higher delay category with each year increase in age (odds ratio 0.94 per year increase; 95% confidence interval 0.91-0.98; adjusted $P = 0.01$). There was no association between number of children per PR and diagnostic delay (adjusted $P = 0.35$; Figure 1). There was also no association between sex and diagnostic delays in a multivariate model accounting for these other factors considering a P value cutoff of less than 0.05. However, age, sex, race, and distance traveled all enhanced model fit using the criteria of decreasing the model AIC by more than two points, suggesting that sex and race might also be associated with diagnostic delay. Density of PRs and Hispanic ethnicity did not enhance model fit by this criteria. There was no evidence of residual spatial autocorrelation in this model by Moran's I test ($P = 0.08$), so a spatial term including smoothed latitude and longitude was not included in the model.

The Pearson correlation coefficient between distance traveled and state density of PRs was 0.13, suggesting a positive but weak correlation between these variables (Supplementary Figure 2). Further investigation of this relationship revealed that many of the states that have few PRs are also sparsely populated, so although the distance traveled is high, the density of PRs is low because of a lower number of children for that state (eg, North Dakota, South Dakota, and Idaho).

Table 1. Patient characteristics stratified by time to diagnosis

	Early (<30 d)	Typical (1-3 mo)	Moderate Delay (3-12 mo)	Severe Delay (>12 mo)	<i>P</i> Value
Subjects, n	81	157	184	72	
Age, median (IQR), y	6.0 (4.0-10.0)	5.0 (4.0-10.0)	5.0 (3.0-9.0)	4.0 (3.0-8.0)	0.04
Female sex, n (%)	51 (64.6)	118 (75.6)	136 (76.8)	43 (60.6)	0.02
Race, n (%)					0.30
White	59 (72.8)	124 (79.0)	150 (82.0)	53 (75.7)	
Black	9 (11.1)	20 (12.7)	21 (11.5)	8 (11.4)	
Other minority	13 (16.0)	13 (8.3)	12 (6.6)	9 (12.9)	
Hispanic ethnicity (%)	14 (17.3)	17 (10.8)	25 (13.6)	16 (22.2)	0.12
Distance from pediatric rheumatology center, median (IQR), mi	42 (17-81)	42 (20-119)	46 (18-124)	41 (18-113)	0.48
kilometers	67.6 (27.4-130.4)	67.6 (32.2-209.9)	74.0 (29.0-228.5)	66.0 (29.0-182.0)	
Population of children per pediatric rheumatologist, median (IQR)	214 994 (142 609-298 318)	249 921 (146 572-399 046)	249 921 (146 572-369 729)	249 921 (161 577-484 672)	0.16

IQR, interquartile range.
 Bold value indicated significance, $p < 0.05$.
 Early = Early Time to Diagnosis
 Typical = Typical Time to Diagnosis

Table 2. Predictors of delay in an ordered GAM

Predictor	OR	95% CI	P Value
Distance (smoothed)		See Figure 1	0.02
Density of rheumatologists (smoothed)		See Figure 1	0.35
Age of JDM onset	0.94	0.91-0.98	0.01
Female sex	0.91	0.63-1.33	0.63
Black race	1.05	0.63-1.75	0.84
Other minority race	0.65	0.36-1.20	0.17
Hispanic ethnicity	1.36	0.83-2.24	0.22

CI, confidence interval; GAM, generalized additive model; JDM, juvenile dermatomyositis; OR, odds ratio.

The OR represents the odds of increasing in one delay category. For the category of race, white race is the baseline category and ORs for Black and other minority races are reported relative to this category. Bold value indicated significance, $p < 0.05$

DISCUSSION

In this study, we have shown that the majority of subjects with JDM enrolled in the CLR between 2010 and 2015 experienced significant diagnostic delays of greater than 3 months. Factors associated with diagnostic delays included younger age at disease onset and greater distance from a treating pediatric rheumatology center. In a univariate analysis, male sex was also associated with delayed diagnosis, although this association did not hold up when controlling for other factors. The sex and age results suggest that JDM may be considered less often in young children and male children, which may be due to the epidemiology of JDM relative to other pediatric rheumatic diseases. These findings are in accordance with other studies that have described diagnostic delays in pediatric rheumatic diseases, including pediatric lupus and

juvenile idiopathic arthritis (6,8), but they emphasize that JDM may be associated with even greater delays.

Our findings show that in JDM, distance traveled to pediatric rheumatologist is associated with time to diagnosis. This is a finding of key importance, as delays in diagnosis are known to be associated with increased morbidity in patients with JDM (4). Prior work has shown poorer outcomes in other chronic pediatric conditions, such as type 1 diabetes mellitus and depression, for individuals who live further distances from their specialists (14, 15). Living greater distances from specialist care likely makes frequent-interval follow-up visits challenging, and close monitoring is necessary in chronic conditions such as JDM to assess and detect disease activity in order to consider modifications in therapy. In addition to increasing the pediatric rheumatology workforce, strategies such as partnering with local adult rheumatologists and primary care providers and performing telemedicine, which has become significantly more prevalent in the era of coronavirus disease 2019, may be possible approaches to narrow this disparity.

Interestingly, living in a state with fewer PRs was not found to be associated with delay to diagnosis, as was the case in pediatric lupus (6). We had initially theorized that patients living in states with a lower density of PRs might be the same patients driving longer distances to a treating center; however, this was not supported by our analysis. Based on our analysis, we found that patients who drove longer distances lived in states with less population density, so the relative density of PRs was not as sparse as one might think.

Younger age at onset was associated with significantly longer time to diagnosis in our study population. Similar findings were reported in patients with SLE (6) and are likely due to the low incidence of JDM and limited recognition of these rare conditions by primary care providers. Increased education and outreach to community providers around the presenting symptoms of JDM, particularly the bimodal age distribution of children affected, rash morphologies, and patterns of weakness, is needed to help remedy this issue.

We recognize that there are limitations to this study. Because we only have information regarding patients enrolled to the CLR, our findings may not be generalizable to the US population as a whole. Definite or probable JDM were not separated at the time of enrollment, so they could not be subanalyzed. Because this was a voluntary registry, there may be selection bias in the patients enrolled, with patients who were English speaking likely being asked to participate at higher rates in addition to other potential factors biasing enrollment. Additionally, almost all patients enrolled to the CLR had insurance, and this analysis may not be generalizable to patients who do not have health insurance. There was also less participation in the CLR from underserved states. Notably, we did not have subjects in our study from 14 states (Alaska, Arizona, Arkansas, Florida, Hawaii, Louisiana, Mississippi, Montana, Nebraska, Nevada, New Mexico, North Dakota, South Dakota, and Wyoming), which have less access to pediatric rheumatology care. Ten of these states had only one or two PRs, and two states

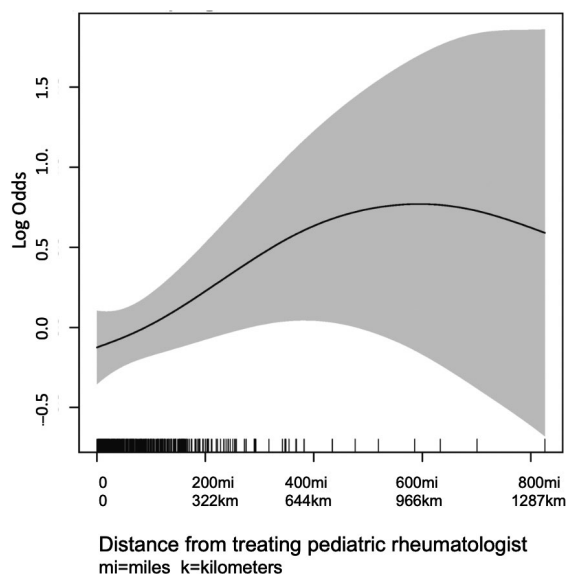


Figure 1. Log odds of increasing by one or more delay categories as distance from treating pediatric rheumatologist increases with surrounding confidence intervals (shaded). There are few observations traveling more than 400 miles.

had no PRs according to the 2015 ACR Workforce Study (13). Many of these states make up the Midwest region of the country, from which we had few observations in which patients may have to travel great distances to reach care (Supplementary Figure 1). We expect that the findings in this study may underestimate the diagnostic delays in these states that are not represented in the CLR.

Additional limitations included missing data, which reduced our total data set to about half the original size; measuring distance by zip code centroid rather than the exact address, which adds some noise to the measurement; and our inability to account for unmeasured confounders (for example, mode of transportation; traffic; access to pediatric primary care; socioeconomic status, such as income and parental education level; primary language; and immigration status) that may have impacted access to care, all of which could introduce possible bias. We also had limited information regarding disease features at JDM presentation. Thus, we could not include details of initial disease presentation in our analysis (eg, severity of disease, presenting rashes, systemic features, arthritis, muscle enzymes, etc). It may be that patients that were sicker presented to care earlier, whereas patients with milder disease experienced more delays regardless of age or distance to referral center. Lastly, these findings may be unique to the US population, limiting the generalizability to the international community.

Despite these limitations, a significant strength of this study is our use of the large national cohort of patients with JDM enrolled in the CLR, which included the typical age and racial diversity reported from other JDM cohorts (16–18), suggesting that the data are representative of patients with JDM in the United States. This study highlights how large disease registries can be integrated with other publicly available data sets, such as geographical data and workforce data sets, to answer important epidemiological questions. Another strength of this work is the multimodal approach to looking at access pediatric rheumatology care using both geospatial data and number of PRs available to a community as measured by density. By using two different variables to address this concept, we hopefully decreased the impact of the unmeasured confounders mentioned above in the overall answering of our initial research question.

Most importantly, our study highlights the significant diagnostic delays experienced by children with JDM associated with several demographic and socioeconomic factors, including access to pediatric rheumatology care. These barriers will require creative solutions from many angles to improve outcomes for children with JDM. First, it is key to increase the pediatric rheumatology workforce throughout the United States. In addition, increasing exposure to pediatric rheumatology in medical schools and residency programs, as well as providing continuing education to primary care providers, will be essential in improving early recognition of JDM, especially in the youngest patients. Using technology such as telemedicine, which providers are becoming increasingly more

adept at, to decrease the burden of travel for patients and partnering with local clinicians may help to improve the frequency of assessments and adjustment of therapy and ultimately decrease functional disability.

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AUTHOR CONTRIBUTIONS

All authors were involved in drafting the article or revising it critically for important intellectual content, and all authors approved the final version to be published. Dr. Susan Kim had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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