

DIAGNOSTIC DELAYS IN VASCULITIS AND FACTORS ASSOCIATED WITH TIME TO DIAGNOSIS



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OBJECTIVES

- Patients with vasculitis continue to encounter diagnostic delays despite advancement in the evaluation and management of vasculitis
- Diagnostic delays are often associated with substantial morbidity and mortality
- This study sought to identify factors associated with diagnostic delays and describe patients' journey through the healthcare system from onset of symptoms to diagnosis with vasculitis
- The overarching goal is to create interventions aimed at shortening the time to diagnosis in patients with vasculitis

METHODS

- Patients enrolled in the Vasculitis Patient-Powered Research Network, an online registry, completed a 2-stage mixed-methods study:
 - Stage 1:** Survey consisting of open-ended questions about patients' diagnostic journeys and factors perceived to be associated with rapid or delayed diagnosis
 - Stage 2:** Survey with specific questions based on data from Stage 1 and additional factors identified by investigators
- Factors associated with diagnostic delays were divided into patient-related factors and healthcare-related factors
- Multivariate linear regression analysis identified factors associated with time to diagnosis
- Patient Research-Partners participated in idea conception, study design, and patient-engagement

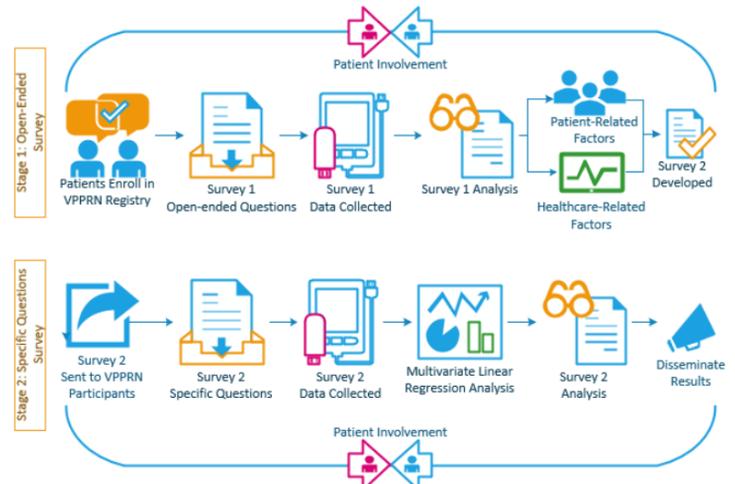


Table 1. Study Subject Demographics

Disease Type	Number of Patients	Mean Age ± SD (Median)	Female N (%)	Caucasian N (%)	Median Time to Diagnosis (Months)	
					Median	Range
Behçet's disease	17	45 ± 13	15 (88%)	15 (94%)	205	3.6 – 619
Central nervous system vasculitis	15	53 ± 11	12 (80%)	13 (87%)	1	0.0 – 38
Cryoglobulinemic vasculitis	15	63 ± 14	13 (87%)	14 (93%)	9	0.0 - 233
Eosinophilic granulomatosis with polyangiitis	58	59 ± 12	40 (69%)	54 (93%)	16	0.0 - 432
Giant cell arteritis	26	70 ± 9	20 (77%)	24 (92%)	2	0.0 – 384
Granulomatosis with polyangiitis	169	56 ± 15	110 (65%)	164 (98%)	6	0.0 – 193
IgA-vasculitis	18	49 ± 19	12 (67%)	17 (94%)	1	0.0 - 17
Microscopic polyangiitis	53	57 ± 14	43 (81%)	52 (98%)	6	1.2 - 244
Polyarteritis nodosa	21	47 ± 20	11 (52%)	19 (90%)	10	0.0 - 108
Takayasu's arteritis	21	43 ± 18	20 (95%)	19 (90%)	9	0.0 - 160
Urticarial vasculitis	15	57 ± 12	12 (80%)	15 (100%)	31	0.0 - 252
Other	17	54 ± 14	15 (88%)	15 (94%)	205	3.6 – 619
Total for All Types of Vasculitis	456	56 ± 15	330 (72%)	432 (95%)	7	0.7 - 281

RESULTS

- **Table 1** describes the patient population and time to diagnosis by disease
- 313/456 (73%) patients were misdiagnosed initially:
 - 33% were diagnosed with infections
 - 29% with an autoimmune disease
 - 11% thought not to have an illness
- The median (IQR) number of misdiagnoses was 5 (3)
- 40% of diagnoses were made in a hospital setting (35% inpatient and 5% emergency room [ER])
- Only 2% of diagnoses were made at a specialized vasculitis center
- More than half of patients had at least 1 ER visit prior to diagnosis, with 5% of patients having > 10 ER visits
- Not having employment, time to travel to a medical center greater than 1 hour, being initially misdiagnosed, and delays in seeing a specialist were all associated with longer times to diagnosis (**Tables 2 & 3**)
- 373/456 (82%) patients reported that a delay in diagnosis had negative consequences on their health: 55% of patients thought it made their condition worse, 16% lost their job, and 11% became disabled

Table 2. Healthcare-related factors associated with time to diagnosis

FACTORS	COEFFICIENT (95% CI)	P-VALUE
Specialist involved initially	-1.3 (-3.1 - 0.6)	0.18
Lab studies ordered initially	0.2 (-1.6 - 2.0)	0.80
Misdiagnosis	2.3 (0.1 - 4.5)	0.03
Referral delays due to insurance	-0.3 (-2.5 - 2.5)	0.98
Time to see a specialist > 1 month	2.4 (0.3 - 4.6)	0.03

A positive coefficient indicates a longer time to diagnosis and a negative one indicates a shorter time to diagnosis. CI: confidence interval.

Table 3. Patient-related factors associated with time to diagnosis

FACTORS	COEFFICIENT (95% CI)	P-VALUE
Female sex	-1.5 (-4.0 - 0.5)	0.15
Caucasian race	-1.5 (-6.0 - 3.0)	0.54
Single or Divorced or Widow(er)	1.1 (-1.0 - 3.2)	0.29
Employed	-2.4 (-4.0 - -0.4)	0.02
Household income >\$50,000/year	-1.5 (-4.2 - 0.6)	0.18
Patient location (North America)	1.2 (-2.0 - 3.8)	0.76
Charlson score >1	-1.5 (-3.9 - 0.4)	0.12
Time to travel to healthcare site >1 hour	2.6 (0.6 - 4.5)	<0.01

A positive coefficient indicates a longer time to diagnosis and a negative one indicates a shorter time to diagnosis. CI: confidence interval.

CONCLUSIONS

- Patients with vasculitis encounter substantial delays in achieving an accurate diagnosis
- Both patient-related factors and healthcare-related factors are associated with diagnostic delays in cases of vasculitis
- Future efforts should focus on mechanisms to address modifiable factors and shorten delays in diagnosis for patients with new-onset vasculitis

FUNDING/ACKNOWLEDGEMENTS

