The Journal of Rheumatology 2025;xx:xxxxxx
doi:10.3899/jrheum.2025-0640
First Release November 15 2025

The Journal of Rheumatology

Navigating the Roadblocks: National Patient and Provider Survey on Barriers to Healthcare and Medication Access for Patients With Vasculitis

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ABSTRACT. ***Objective.*** Timely diagnosis, specialized care, and medication access are critical for managing vasculitis. This study quantified barriers to care reported by patients and healthcare providers (HCPs).

Methods. Two primarily quantitative surveys were disseminated from September 2022 to June 2023 to 100 patients with vasculitis and 31 HCPs, through the Vasculitis Foundation Canada and the Canadian Rheumatology Association. This study was a secondary descriptive analysis of the data to analyze patient and HCP perspectives on diagnostic delays, appointment access, and medication challenges.

Results. Diagnostic delays were common, with 66% of patients reporting initial misdiagnoses, and 35% consulting ≥ 5 doctors before receiving a diagnosis of vasculitis. Among those referred to rheumatology, 57% waited > 1 month for an appointment. HCPs cited a lack of family physicians (74%), long waitlists (58%), and inappropriate referrals (48%) as major barriers. Forty-four percent of patients reported challenges associated with medication use, particularly related to adverse effects, out-of-pocket costs, and limited insurance coverage. Eighty-three percent of patients reported hospital visits at least once for vasculitis-related symptoms, most commonly due to disease flare. Eighty percent of HCPs reported challenges with prescribing or accessing medications for vasculitis, including issues associated with prior authorizations and step therapy protocols. Rituximab was the most commonly mentioned medication associated with these challenges.

Conclusion. This study identified substantial barriers to vasculitis care, including diagnostic delays and limited access to medications. Targeted interventions, such as improving referral pathways, expanding provider availability, and reducing administrative burdens, are essential to improving access for this vulnerable population.

Key Indexing Terms: drug therapy, health services accessibility, insurance, surveys and questionnaires, vasculitis

Access to health care is a critical component in the management of vasculitis, a group of rare autoimmune diseases characterized by inflammation of blood vessels.[1,2] Effective management relies on timely diagnosis, access to specialized care, and the availability of disease-modifying antirheumatic drugs (DMARDs) and biologics.[3,4] However, several barriers hinder patients' ability to receive the care they need, leading to delays in diagnosis, increased hospitalizations, and challenges in obtaining timely, appropriate treatments.[5-7]

Diagnostic delays are common among patients with vasculitis, often due to nonspecific symptoms and the condition's tendency to resemble other illnesses.[7,8] These factors can often lead to provisional diagnoses or misdiagnoses before reaching a final diagnosis of vasculitis. Such delays can prolong disease activity and worsen outcomes, as early and accurate treatment are essential to managing disease progression. Patients may also encounter further delays in care due to difficulties securing appointments with specialists such as rheumatologists, exacerbated by provider shortages and long waitlists.

Access to medications presents another significant barrier.[7,9] Many patients face challenges in obtaining DMARDs and newer therapeutic agents, whether due to lack of insurance coverage, high out-of-pocket costs, or the need for prior authorizations. These financial and administrative hurdles often lead to treatment delays, suboptimal care, or nonadherence, all of which can contribute to disease progression and increased hospitalizations.[7] For healthcare providers (HCPs), navigating these barriers are time-consuming and can complicate the overall management of vasculitis.[10-12]

Understanding these barriers is critical for developing targeted interventions that improve healthcare access. This study sought to understand and quantify the challenges experienced by both patients and HCPs in accessing timely care and medications, with the aim of informing strategies that enhance

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Accepted for publication September 17, 2025

treatment delivery and optimize outcomes for individuals with vasculitis.

METHODS

Study design. This study was a secondary analysis of data collected through previously administered national surveys designed to explore barriers to care among patients with vasculitis and the HCPs who treat them. The original study by Nanda et al examined Canadian patient and provider perspectives on the effect of social determinants of health on access to vasculitis care and employed a quantitative descriptive design that has been described in detail elsewhere.[13] Briefly, 2 surveys were developed collaboratively by experts in vasculitis and survey methodology, following a systematic process that included a literature review, pilot testing, and further refinement. The final surveys consisted primarily of multiple choice questions, including those for demographic or profiling of respondents, and others with Likert scales to rate different aspects of care and treatment as being "not at all a barrier," "somewhat of a barrier," or "a major barrier." Open-ended responses related to logistical access were included to supplement the quantitative findings and provide contextual understanding.

Participants were recruited through convenience and purposive sampling, with surveys distributed via email to members of the Vasculitis Foundation Canada (VFC), Canadian Rheumatology Association (CRA), and CanVasc, as well as distributed though VFC's social media accounts. The patient survey included adults diagnosed with vasculitis, and the HCP survey included physicians involved in vasculitis care. Inclusion was based on self-confirmed diagnoses and HCP roles, respectively.

Data collection and analysis. The present study focused specifically on a subset of survey items related to logistical and medical access barriers (eg, delays in referrals, specialist access, appointment availability) that had not yet been reported. Data from the original study[13] was collected via REDCap and analyzed using descriptive statistics in Microsoft Excel 2022.

RESULTS

Demographics. Between September 27, 2022, and March 31, 2023, the patient survey was initiated by 139 individuals and completed by 100 participants, for an estimated response rate of 72%. Most respondents were female (80%), aged 40-64 years (46%), White (88%), and residing in Ontario (57%) and urban areas (55%). Common vasculitis diagnoses included granulomatosis with polyangiitis (38%), microscopic polyangiitis (15%), Behçet disease (8%), and giant cell arteritis (7%). Sixty-three percent reported having comorbid conditions. Self-rated health was fair (39%), good/very good (40%), or poor/very poor (21%).

The HCP survey was conducted from February 21 to June 9, 2023. This survey was initiated by 41 members of the CRA and CanVasc, of whom 31 completed the survey, for an estimated response rate of 76%. Most were rheumatologists (94%) from urban centers (87%) in Ontario (33%), with experience ranging from residency to > 20 years in practice.

Diagnostic delays. Most patient respondents were diagnosed within the past 5 years (53%), with 22% diagnosed 5-10 years ago, 13% 10-20 years ago, and 12% over 20 years ago. As shown in Table 1, two-thirds of patients reported being misdiagnosed at initial presentation with symptoms of vasculitis. The most frequent initial misdiagnoses included infectious conditions, allergies, cancer, arthritis, fibromyalgia, and mental health conditions such as depression or anxiety. Additionally, 19% of participants were informed that there was "nothing wrong." Over one-third (35%) of participants consulted ≥ 5 doctors before receiving a correct diagnosis of vasculitis, whereas 21% were diagnosed after seeing 1-2 doctors.

Although 45% were diagnosed by a rheumatologist, others received diagnoses from nephrologists, internists, or emergency physicians. Of the patients referred to rheumatology, 57% waited over 1 month, including 11% who waited 3-6 months. Time to diagnosis varied such that one-quarter of patients were

Table 1. Patient perspectives on diagnostic delays in vasculitis care.

Diagnosis and Access-Related Survey Items	% of Responses (n)
Time to vasculitis diagnosis (n = 100)	
> 3 yrs	21 (21)
1-3 yrs	12 (12)
6-12 mos	21 (21)
3-6 mos	20 (20)
< 3 mos	26 (26)
Initial provisional diagnosis (misdiagnosis) (n = 96)	
Yes	66 (63)
No	34 (33)
Reported initial misdiagnoses (n = 63)	
Allergies	19 (12)
Arthritis	6 (4)
Cancer	11 (7)
Depression/anxiety	5 (3)
Infection	27 (17)
Fibromyalgia	5 (3)
"Told there was nothing wrong"	19 (12)
Other	29 (18)
No. of doctors seen prior to diagnosis of vasculitis (n = 99)	
1	4 (4)
2	17 (17)
3	32 (32)
4	11 (11)
≥ 5	35 (35)
Physician who diagnosed vasculitis (n = 100)	
Emergency medicine physician	4 (4)
Internist	10 (10)
Nephrologist	16 (16)
Family physician	4 (4)
Pulmonologist	7 (7)
Rheumatologist	45 (45)
Other	14 (14)
Wait time to rheumatology appointment, mos (n = 89)	
< 1	43 (38)
1-2	25 (22)
2-3	9 (8)
3-6	11 (10)
> 6	6 (5)
Other	7 (6)

diagnosed within 3 months, whereas one-fifth were diagnosed within each of 3-6 months, 6-12 months, or > 3 years. Another 12% were diagnosed within 1-3 years.

Several key factors contributing to delays in rheumatology appointments were identified by HCPs, as described in Table 2. The most frequently reported reason stated was that the patient did not have a family physician, cited by 74% of all respondents. Additionally, 65% of HCPs indicated "patients not being referred to a rheumatologist earlier" as a reason for appointment delays. Other notable reasons included long waitlists in rheumatology clinics (58%) and inappropriate referrals of patients who did not need to see a rheumatologist (48%). Geographic inaccessibility of rheumatologists, despite their availability, was identified by 39% of respondents, whereas 32% noted the unavailability of rheumatologists as a factor.

Most HCPs noted triaging new referrals themselves or by their physician colleagues. Wait times for nonurgent referrals varied such that 39% of providers stated that patients were seen within < 1 month in their clinic, whereas 29% reported wait times between 1 and 2 months, and 19% between 3 and 6 months. For urgent referrals, although most HCPs (86%) noted that patients were seen within 7 days of being referred, about half reported a wait time of 48 hours or less.

Barriers to care. Patient and HCP perspectives on barriers for patients in accessing care for vasculitis are shown in the Figure. Patients reported travel (51%), clinic wait times (42%), mobility issues (41%), appointment delays (42%), and need to take time off work (37%) as barriers. Fewer cited lack of follow-up (6%), discrimination (7%), or uncomfortable environments (9%). HCPs noted similar barriers but emphasized systemic barriers. Travel (100%), family responsibilities (87%), limited health literacy (93%), appointment delays (90%), limited clinic hours (73%), and short appointment duration (62%) were cited as barriers for patients by HCPs. Although both groups recognized issues like long clinic wait times and appointment delays to be barriers, more HCPs compared to patients viewed these barriers as major.

HCPs reported several other barriers in the provision of vasculitis care. The lack of timely referral was cited by 94% of respondents as a barrier, with 23% of respondents noting it to be a major barrier. An administrative burden for medication approval was also frequently reported (94%), including 45% indicating it as a major barrier. Inadequate appointment duration was noted by 68% of providers, with 23% identifying it as a major concern. Although 65% cited limited pharmaceutical support as a barrier, only 13% considered it a major barrier.

Some HCPs also reported a perceived lack of evidence-based guidelines (52%) and limited awareness of treatment options (32%) as "somewhat of a barrier." Additional barriers mentioned in open-end responses included limited access to laboratory tests and restrictive criteria for advanced therapeutics, highlighting financial and logistical challenges. A few HCPs also noted fragmented communication between specialities due to the lack of a unified electronic medical record, complicating the coordination of care.

Barriers to medication access. Forty-four percent of patients reported difficulties accessing or using medications. Rituximab was cited as a medication of concern by 45% of patients, with limited access due to poor or a lack of insurance coverage being the most frequent concern (55%, n = 11). Though 82% had a drug coverage insurance plan, 57% reported restrictions or exclusions on the use of certain medications. Open-ended responses from patients also reported a lack of counseling on side effects and low evidence on medication effectiveness as common themes.

Regarding acute care access, 83% of patient participants had visited the emergency department or had been hospitalized due to vasculitis symptoms; 52% were due to disease relapse. Twenty-eight percent had > 3 hospitalizations. Cumulative hospital stay duration varied such that 45% stayed for < 2 weeks, 19% for 2-4 weeks, 12% for 1-2 months, and 5% for > 3 months. Ten patients received in-hospital treatments not covered by insurance, and 6% could not afford discharge medications.

Over three-quarters of HCPs (80%) reported facing challenges in prescribing medications for patients with vasculitis. The most frequently cited barrier was a lack of coverage by the patient's insurance, particularly for medications such as rituximab (58%), mycophenolate mofetil (26%), and adalimumab (19%). The requirement of step therapy prior to insurance approval was also commonly reported. Inconvenience and challenges of administering the medication to patients were noted by 32% of providers for rituximab and 26% for cyclophosphamide.

Administrative barriers were also noted by HCPs as

Table 2. Healthcare provider perspectives on appointment delays, wait times, and referral times in vasculitis care (n = 31).

Appointment and Referral-Related Survey Items	% of Responses (n)
Perceived reasons for appointment delays	
Patients not having a family physician	74 (23)
Patients not being referred to a rheumatologist earlier	65 (20)
Rheumatologist not being available	32 (10)
Rheumatologists being available but not accessible geographically	39 (12)
Patients who do not need to be seen by a rheumatologist being referred to rheumatology clinics	48 (15)
Long waitlist in rheumatology clinic	58 (18)
Other	6 (2)
Wait times for nonurgent referrals, mos	
< 1	39 (12)
1-2	29 (9)
2-3	13 (4)
3-6	19 (6)
Wait times for urgent referrals	
24 h	16 (5)
48 h	35 (11)
5 d	19 (6)
7 d	16 (5)
8-14 d	6 (2)
Other	6 (2)
Responsible for referral triage	
Physician	94 (29)
Triage nurse	3 (1)
Other	3 (1)

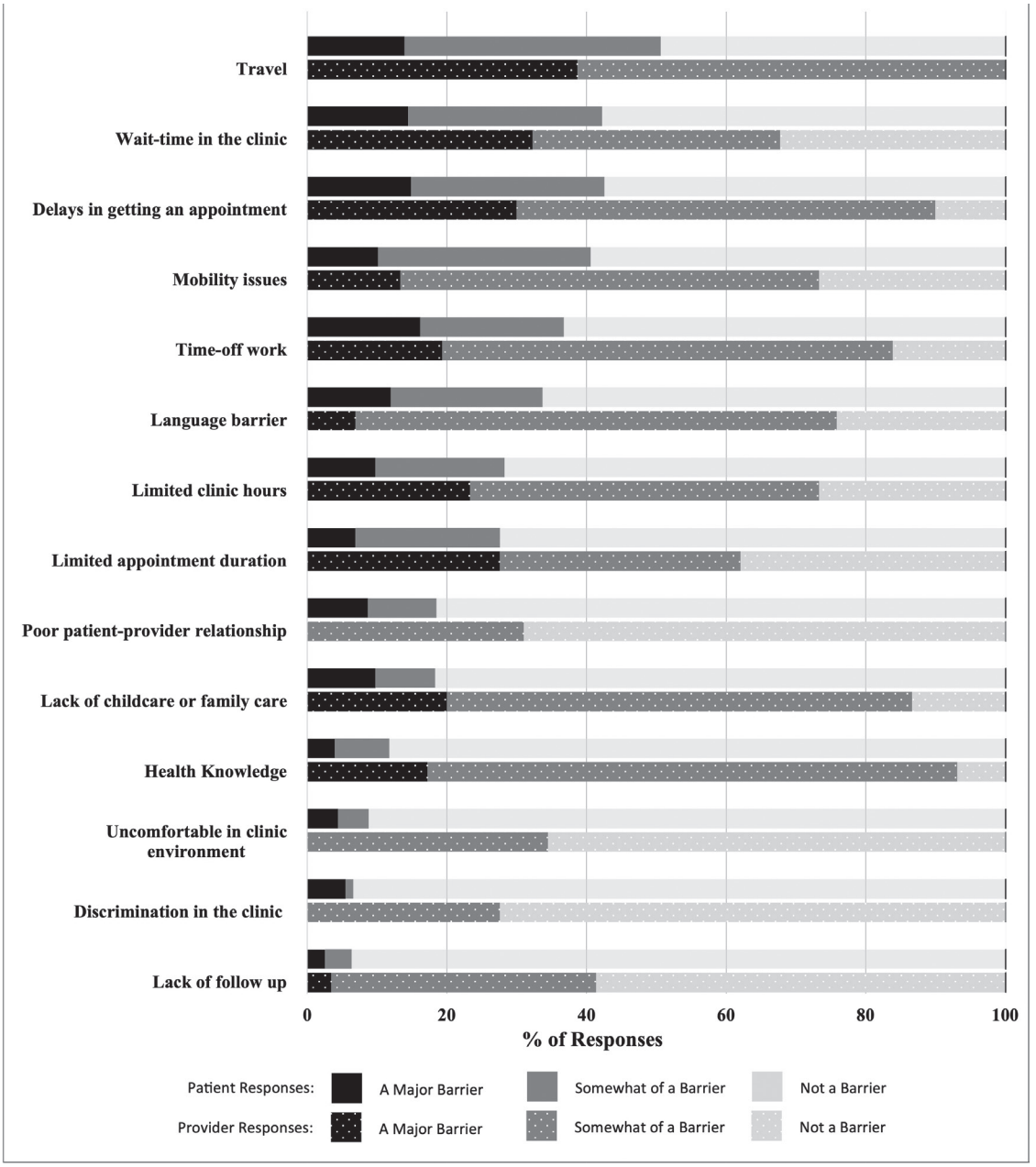

Figure. Barriers to care as reported by patients with vasculitis (n = 100) and HCPs (n = 31). Respondents rated each factor as "a major barrier," "somewhat of a barrier," or "not a barrier." Solid bars represent patient responses, and dotted bars represent HCP responses. HCP: healthcare provider.

presenting significant challenges for HCPs managing patients with vasculitis. Fifty-two percent reported that they had no support for completing the forms required to request or access medications, with all forms being completed by the physician alone. Twenty-three percent of respondents indicated receiving assistance from a medical office assistant, and 19% reported support from a registered nurse or a pharmaceutical company. Despite this limited support, 68% of respondents expressed the need for additional help in completing these forms.

DISCUSSION

This study highlighted the perspectives of patients and HCPs regarding significant barriers to healthcare access and medication availability for patients with vasculitis in Canada. Diagnostic delays emerged as a critical barrier in the study, with 66% of patients noting they were initially misdiagnosed and more than one-third consulting 5 or more doctors before receiving an accurate diagnosis. These findings reflect diagnostic challenges in vasculitis, where symptom presentation may be nonspecific and overlap with more common conditions.[14-17] Notably, 19% of participants were told that there was nothing wrong when initially seeking care, highlighting the potential for dismissal or misinterpretation of early symptoms. Delays were further exacerbated by long wait times to see rheumatologists,

with 57% of patients waiting over a month following referral. HCPs similarly noted these trends, emphasizing the need for streamlined referral pathways, improved primary care engagement, and targeted education to facilitate earlier recognition and intervention.

Patients and HCPs alike identified logistical challenges, such as travel distance, clinic wait times, and needing time away from work as key obstacles. These challenges disproportionately affect patients with mobility limitations, those in rural communities, or individuals with comorbidities.[18-20] Many patients, especially those in remote or rural areas, reported difficulty accessing rheumatology care due to long travel distances and limited availability of specialists. Although telemedicine has helped mitigate some of these issues, its limitations, particularly in performing essential physical exams, underscores the need for a balanced approach to managing vasculitis care remotely.[21,22] HCPs further emphasized barriers related to limited clinic resources, appointment availability, and administrative workload. The gap in support for administrative tasks, reported by over half of HCPs, further contributed to delays, and reduced the time available for direct patient care.

Medication access also poses significant challenges for patients and HCPs. Forty-four percent of patients reported difficulties obtaining or using their prescribed treatments, especially bDMARDs such as rituximab. Common challenges included lack of insurance coverage, out-of-pocket costs, adverse effects, and limited counseling about treatment risks and benefits. Although 82% of patients had drug plans, the majority (57%) reported exclusions or restrictions. Administrative burdens, such as prior authorizations and step therapy requirements, were prominent obstacles to accessing medications. More than two-thirds of HCPs expressed a need for additional support in managing these administrative tasks such as completing required forms, which can exacerbate delays in patient care or access to required treatments.

The downstream consequences of these access issues were evident in hospitalization data. Eighty-three percent of patients had been hospitalized or visited the emergency department at least once due to vasculitis, with 52% attributing their visit to a disease relapse. There were 28% with > 3 hospitalizations, and 5% reported cumulative hospital stays longer than 3 months. These findings suggest that poor access to outpatient care and medications may contribute to preventable relapses and increased acute care use, representing a substantial burden on both patients and the health system.[17]

To address these barriers, systemic changes are necessary, including increasing the availability of family physicians and rheumatologists, improving referral processes, and expanding insurance coverage for critical therapies. Streamlining administrative tasks through better organizational support and integrating unified electronic medical records may reduce the burden on providers and improve coordination of care. Additionally, addressing logistical challenges, such as travel and mobility issues through expanded telemedicine options and patient-centered services, may further enhance access to care. By addressing these barriers through targeted interventions and policy reform, healthcare systems may improve access, reduce avoidable hospitalizations, and ultimately enhance the quality of life for patients with vasculitis.

This secondary analysis expanded on the original study, which focused on social determinants of health, by providing a complementary, systems-level perspective on access to care to examine systemic, logistical, and structural barriers such as diagnostic delays, provider shortages, and medication access issues. In interpreting these findings, methodological limitations should be considered. Recruitment through patient organizations, social media, and email lists may have introduced selection bias, favoring individuals who are more engaged in their care, currently facing challenges, or have higher digital literacy. As a result, the sample may not fully represent all Canadians with vasculitis, particularly those in remission or those less connected to advocacy groups. Although most participants were diagnosed within the past 5 years, recall bias remains a possibility for those with longer disease histories. The response rate was estimated based on survey initiation, as calculating the exact sample size was difficult due to overlapping recruitment networks. Despite these limitations, the consistency and depth of the responses collected across both patient and provider groups reveal important patterns.

In conclusion, from diagnostic delays to medication access, the findings show gaps in the delivery of care for a vulnerable patient population with a complex, rare, and often severe autoimmune disease.

CONTRIBUTIONS

KN: conceptualization, data curation, investigation, validation, writing - original draft, review, editing; PM: formal analysis, methodology, validation, writing - original draft, review, editing; KKB: methodology, validation, writing - original draft, review, editing; CP: formal analysis, investigation, validation, writing-original draft, review and editing; JS: conceptualization, data curation, validation, writing - original draft, review and editing; EY: conceptualization, formal analysis, supervision, investigation, methodology, validation, writing - original draft, review and editing.

FUNDING

The authors declare no funding or support for this research.

COMPETING INTERESTS

The authors decare no conflicts of interest relevant to this article.

ETHICS AND PATIENT CONSENT

Ethical approval for the study was obtained from the University of Alberta Research Ethics Board (Pro00122345). Patient consent was implicit upon survey completion.

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