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RESEARCH ARTICLE

# An Ethnographic Study of US Adults with Arteriovenous Malformations

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ABSTRACT: Arteriovenous malformations (AVMs) are rare vascular conditions that pose diagnostic and treatment challenges. Existing research on AVMs focuses on medical outcomes and treatment, but few studies explore the patient experience in depth. This study adds to the existing literature by examining how socioeconomic, geographic, and demographic factors shape the experiences of AVM patients. I interviewed six participants with diverse ethnic, geographic, and socioeconomic backgrounds. The sample included one Hispanic woman, one Indian woman, one East Asian man, two white men, and one white woman. Participants shared details about their symptoms, diagnostic journeys, treatment, and daily life changes. I then identified patterns and gaps in care. The findings revealed significant diagnostic delays and frequent misdiagnoses, regardless of the location of the AVM. Rural participants faced additional challenges, including travel burdens and limited access to specialized care. Socioeconomic status influenced treatment affordability and family dynamics during recovery. Findings are consistent with national trends, such as a higher risk of AVM hemorrhage among Hispanic individuals. Participants also reported long-term impacts on physical, emotional, and financial well-being. This research emphasizes the need for equitable healthcare policies and increased awareness of AVM challenges.

KEYWORDS: Behavioral and Social Sciences, Sociology, Medical Anthropology, Ethnography, Arteriovenous Malformation.

## Introduction

Arteriovenous malformations (AVMs) are a rare and complex vascular condition characterized by tangled arteries and veins that disrupt normal blood flow and oxygen circulation in the body. If left untreated, AVMs can lead to serious health complications, including hemorrhages, seizures, stroke, or death.[1] Even though the causes are poorly understood, AVMs affect an estimated 1 in 100,000 people in the United States, occurring slightly more frequently in men than in women.[2] People are usually diagnosed in their young adult years, with many patients undergoing a lengthy treatment process that may involve surgery, radiation, or embolization to reduce the risk of life-threatening complications.[3] Certain AVM locations, such as the brainstem, are considered particularly high-risk due to their proximity to critical neurological structures. Other high-risk angiographic features—such as deep venous drainage and associated aneurysms—have been linked to an increased likelihood of hemorrhage, though risk levels can vary substantially between patients. Clinical decision-making often incorporates hemorrhage risk analysis to help direct treatment planning and balance the potential benefits with procedural risks.

A 2020 study of different management modalities for brainstem AVMs demonstrated varying long-term outcomes and emphasized the importance of individualized treatment plans, considering factors such as AVM size, location, and patient health status[4] Coordinated multidisciplinary evaluation and individualized planning can result in safe and effective treatment of children with AVMs.[5] These personalized approaches enhance the health-related quality of life, reinforcing the need for tailored medical strategies in managing AVMs. Despite advances in AVM treatment, research remains limited regarding the holistic, day-to-day experiences of adults living with this condition. Resources, awareness, and support systems specific to AVM patients need improvement, as individuals are often left to navigate the social, emotional, and financial complexities of this rare disease largely on their own. Because diagnosis may be difficult— often occurring incidentally during routine screening for unrelated issues—and the causes are not well understood, patients may face additional uncertainty, self-blame, and misinformation. The relative rarity of AVM can also contribute to social isolation and potential stigmatization.

Existing studies on AVMs frequently emphasize medical outcomes, providing minimal focus on patient-centered perspectives such as quality of life, emotional well-being, and economic stability. In a 2011 study, The Values and Value of Patient-Centered Care, it is said that patient-centered care must be rooted in "deep respect for patients as unique living beings," where patients are seen in the context of their social worlds, listened to, respected, and actively involved in their care.[6] Despite advances in diagnosis and treatment, little is known about how adults with AVMs navigate the personal, social, and systemic challenges of living with this rare condition. This study seeks to answer the following questions: (1) How do adults with AVMs perceive and experience the process of diagnosis, particularly when it occurs incidentally or after misdiagnosis? (2) In what ways do AVMs affect social relationships, emotional well-being, and identity, including experiences of stigma or isolation? (3) What economic and logistical barriers do patients face in accessing specialized care, and how do these shape treatment decisions? (4) How do support systems—both



DOI: 10.36838/IJHSR84.1

formal (healthcare providers, patient organizations) and informal (family, peers) influence coping and quality of life? By addressing these questions, this ethnographic research aims to illuminate the unmet needs of AVM patients, provide insights for patient-centered care strategies, and inform policies and programs that could improve both clinical and non-clinical outcomes.

Using in-depth exploration of the social, emotional, and economic factors influencing these patients, this research provides insight into their primary priorities, challenges, and support needs. By capturing these individuals' narratives, the study highlights the importance of patient-centered approaches in AVM research. It sheds light on the broader implications for healthcare providers, policymakers, and support organizations dedicated to improving the quality of life for AVM patients.

By highlighting previous studies on similar topics, researchers can emphasize the broader context in which the study is placed, showing awareness of key findings, methods, and ongoing discussions. This process not only strengthens the validity of the research but also stresses its significance by addressing gaps or expanding on current knowledge. In the context of AVMs, while existing literature mainly focuses on medical outcomes and treatment approaches, there is a significant lack of research revolving around the lived experiences of patients.

The study "An Ethnographic Study of Patient Life Experience in Early-Stage Parkinson's Disease in the United States and Germany" and this research share a focus on using ethnographic methods to examine how cultural, social, and geographic factors shape patient experiences with chronic conditions, with both highlighting the influence of identity markers like ethnicity and socioeconomic status on diagnosis and treatment.[7] However, while "An Ethnographic Study of Patient Life Experience in Early-Stage Parkinson's Disease in the United States and Germany" explores a rare vascular condition, the Parkinson's paper delves into patients' adaptation to their prognosis and emerging therapies. Similarly, "An Ethnographic Approach to Understanding the Illness Experiences of Patients with Congestive Heart Failure and Their Family Members" examines illnesses through lived experiences, involving patients and families to understand their broader impact.[8]

Both studies uncover themes of adjustment, though this study emphasizes systemic barriers like misdiagnosis and geographic inequities, while the heart failure study focuses on the emotional and relational dynamics of managing the condition. "The Significance of Everyday Life—An Ethnographic Study of Participation in Group-Based Patient Education" also aligns in its emphasis on social context and meaning-making, though it centers on group-based education programs.[9] On the other hand, the current study investigates disparities in care shaped by external factors like location and socioeconomic status.

Additionally, "Chronic Disease and Self-Injection: Ethnographic Investigations into Patient Experience During Treatment" provides a holistic examination of the patient's experience at each stage of the treatment pathway, identifying challenges inherent in self-injecting biologics. This study offers valuable insights into patient-reported difficulties and suggests services and devices that could support and improve the self-injection experience, complementing the current research study's focus on patient experiences with AVMs.[10]

Furthermore, "An ethnographic study exploring the experiences of patients living with cancer illness in support group settings in KwaZulu-Natal, South Africa" examines the experiences of cancer patients within support groups, shedding light on the social and emotional aspects of living with a chronic illness. This study's emphasis on the importance of social support networks aligns with findings in the current ethnographic study revolving around AVMs regarding the role of community and family in managing AVMs.[11]

Moreover, "Online Ethnography for People with Chronic Conditions: Scoping Review" profiles the existing evidence on the application of online ethnography for individuals with chronic conditions. It focuses on the characteristics, contributions, and implementation processes of online ethnography, providing recommendations for its future use. This study highlights the potential of digital platforms in understanding patient experiences, which could be relevant for exploring the narratives of AVM patients in virtual communities.[12]

Lastly, "An Ecosystem of Accepting Life with Chronic Pain: A Meta-Ethnography" parallels the current ethnographic research in its exploration of sociopolitical influences on chronic illness experiences, though this research specifically examines AVMs and the tangible impacts of diagnostic delays and care access, while the chronic pain study provides a broader view on the management of chronic conditions.[13]

## Methods

This ethnographic study, aimed at exploring the lived experiences of adults with arteriovenous malformations (AVMs), used structured interviews to gather consistent, in-depth data from participants. To ensure ethical measures and participant safety, the study was approved by an Institutional Review Board (IRB). An IRB committee evaluates research methods to protect participants' rights, specifically for studies involving human subjects and sensitive medical or personal topics. Given the sensitivity of AVM-related experiences, an IRB committee was necessary for addressing any psychological or emotional risks participants might encounter while sharing their stories. Additionally, all participants provided written informed consent before participation, ensuring they fully understood the study's purpose, procedures, and their rights throughout the research process.

The IRB committee for this research comprised three members: an epidemiologist at the University of Arizona, a pediatrician from Kaiser Hospital, and an independent reviewer. This diverse committee provided oversight, particularly into medical and social concerns relevant to AVM patients. Approval from the committee involved submitting multiple signed forms, including a risk assessment form, a human participant form, a qualified scientist form, and a copy of the pre-interview survey and interview questions. These documents identified potential risks and their respective protections, and the study design met ethical standards for conducting research with human participants in September 2024. Additionally, all

participants provided written informed consent prior to participation, ensuring they fully understood the study's purpose, procedures, and their rights throughout the research process.

Most participants were recruited in collaboration with the Aneurysm and AVM Foundation. Due to the low prevalence of AVMs, the only inclusion criterion was prior diagnosis of AVM. The final sample consisted of six adults with AVMs, ages ranging from 18 to 46 years old. Participant demographics are summarized in Table 1. Participants were informed about the study's purpose, potential risks, and their rights as participants. Interviews were conducted via Zoom to accommodate the participants' geographic locations and lasted between 30 minutes and an hour. They were voice-recorded with participants' consent to ensure accurate data collection. Before each interview, participants completed an online pre-interview survey to provide demographic data such as age, gender, and basic medical history. This preliminary step provided context for each participant's experiences while helping structure interview questions based on their background. Participants were informed that their names and any personal identifying information would remain confidential and would not be disclosed in the research paper or any related publications. This confidentiality assurance was intended to create a safe and respectful environment, encouraging participants to share openly about their experiences.

**Table 1:** This table summarizes the demographic characteristics of the six adult participants, including age, gender, ethnicity, geographic location, and time since AVM diagnosis.

| | |
|---|---|
| Age (years) | |
| Mean (SD) | 32.5 (14.1) |
| Range | 18-46 |
| Gender, n (%) | |
| Female | 3 (50%) |
| Male | 3 (50%) |
| Ethnicity, n (%) | |
| White | 3 (50%) |
| Black | 0 (0%) |
| Hispanic/Latino | 1 (16.6%) |
| Asian-American | 2 (33.3%) |
| Proximity to city, n (%) | |
| Rural | 3 (50%) |
| Suburban | 2 (33.3%) |
| Urban | 1 (16.6%) |
| Years since diagnosis, n (%) | |
| Less than 5 | 2 (33.3%) |
| 5 to 10 | 3 (50%) |
| More than 10 | 1 (16.6%) |

Participants were recruited through an AVM foundation and completed a pre-interview survey to provide this background information. Questions were sent in written form to participants with communication challenges, such as speech impediments, allowing them to respond in writing. This adjustment ensured that all participants could communicate freely, respecting individual needs and communication preferences. Furthermore, one participant, who had experienced being diagnosed with AVM at a young age, expressed discomfort discussing certain hospital experiences. The interview was adjusted to honor this participant's boundaries and focus on areas of comfort.

Structured interview questions were then developed to explore areas such as personal experiences with AVMs, support systems, and reflection on life goals after the AVM (Table 2). These questions provided consistency across interviews, enabling comparison while allowing for depth in individual responses. All interviews were manually transcribed from voice recordings to enable thorough analysis and to draw meaningful conclusions from participant narratives. Key themes were identified to highlight similarities and specificities within the group.

**Table 2:** Structured interview. Questions explored participants' AVM experiences, goals, and treatment journeys. Accommodations such as the use of written responses or adjusted topics were made to ensure accessibility and respect for participant comfort and communication needs.

| | |
|---|---|
| Diagnosis Story | 1. Did you experience any symptoms before your diagnosis? If yes, what were they?<br>2. What did you initially think was causing your symptoms?<br>3. Can you describe the process of getting diagnosed with an AVM? |
| Diagnosis Process | 1. How do you think your social class affected your ability to pay for your treatment?<br>2. What were your goals and motives in life before your diagnosis?<br>3. How have your goals and motives in life changed after your diagnosis? |
| Post Diagnosis | 1. What treatment options were proposed to you?<br>2. Did you have to travel (Distance? far/close)<br>3. Which treatment option did you decide to proceed with and why?<br>4. How did your daily routine change after your diagnosis and treatment?<br>5. What information did you use to research AVMs? What sources did you find most helpful? |

## Results and Discussion

This study examines the social, emotional, and economic impacts of AVM diagnosis on six participants, revealing both shared experiences and individual differences. Across all cases, participants experienced significant physical and emotional challenges. One participant even said it was the "worst headache of [their] life." Symptoms such as severe headaches, vision impairments, and physical limitations were common, with many participants facing long-term effects like fatigue, memory issues, and difficulty performing daily tasks. Emotional struggles, including fear, frustration, and stress, were shared among all as participants navigated the complexities of their diagnoses and treatments. For instance, Participant 2 and Participant 5 had to re-learn basic activities like walking and talking, while others, like Participant 1 and Participant 6, had to alter their daily routines due to lingering fatigue and physical discomfort. Adjustments to daily routines were a consistent theme, ranging from changes to work or school schedules to


DOI: 10.36838/IJHSR84.1

specific health precautions. Participant 1 and Participant 3 made lifestyle changes to protect their health, such as avoiding physical strain and prioritizing rest post-diagnosis.

Travel for treatment was another shared challenge, with most participants requiring trips to access specialized care. Travel distances to healthcare varied between participants, from 60-minute drives to Participant 1 and Participant 6 had several hours of travel for Participant 2 and Participant 5, with the latter needing flights to another state. Rural participants, like Participant 1 and Participant 6, faced significant travel burdens, with commutes of 60 minutes or more to access specialized care, adding financial stress to their families as well as delayed access to medical care.

In contrast, urban participants like Participant 2 and Participant 4 benefited from proximity to medical resources but still encountered diagnostic delays and errors. For example, Participant 2's prolonged diagnostic journey involved extensive traveling to consult multiple specialists over 18 months. These findings emphasize that although diagnostic barriers are a common issue, irrespective of geographic location, rural patients often face additional burdens due to limited healthcare infrastructure. Socioeconomic factors influenced access to care and recovery experiences. Insurance coverage provided financial assistance for some, like Participant 3 and Participant 4, but others experienced significant financial sacrifices. For example, Participant 1's family had to miss work to support her treatment, leading to a financial burden as they were not able to work remotely, and insurance covered only a small percentage of the cost.

Family and medical professionals were crucial sources of support for all participants. Some individuals turned their experiences into advocacy efforts. Participant 2 started a nonprofit organization to raise awareness and fund research on AVMs, and Participant 5's mother founded an AVM support organization. These efforts reflect a take-charge approach to coping and a desire to help others navigate similar challenges.

Patient advocacy groups like The Aneurysm and AVM Foundation (TAAF) play a vital role beyond individual efforts by connecting patients to specialized medical care and facilitating peer support networks that reduce feelings of isolation. These groups also help shape research agendas by funding studies and raising awareness within the medical community. Importantly, they have the potential to address disparities in access to care by reaching underserved populations and advocating for equitable healthcare resources. Through education, community-building, and advocacy, patient groups empower individuals and families affected by AVMs to navigate the complexities of diagnosis and treatment more effectively. While there were many similarities in how AVMs affected participants, there were also notable differences (Table 3). Diagnosis timelines varied widely. Most participants faced delays in diagnosis, often due to misdiagnosis or prolonged diagnostic journeys. Participant 5 was initially misdiagnosed with just a headache and was treated with Tylenol, while Participant 6's symptoms were dismissed as growing pains. Participant 2's diagnostic process lasted 18 months and required consultations with multiple specialists, including pediatricians, neurologists, and an ENT, before an MRI/MRA confirmed the correct diagnosis. In contrast, Participant 1, Participant 4, and Participant 3 received relatively quicker diagnoses due to clear symptoms of severe events such as strokes. These diagnostic challenges highlight the importance of raising awareness about AVM symptoms to improve early detection and treatment. The age of diagnosis also ranged from early teens (for Participant 2 and Participant 5) to adulthood (for Participant 4 and Participant 3), shaping how participants responded to their conditions.

Participants' goals and life adjustments in response to the condition also varied. For Participant 1, long-term goals like attending college and starting a family remained unchanged, while Participant 3 and Participant 4 shifted their focus from advancing careers to prioritizing health and family. Teen participants, Participant 2 and Participant 5, initially sought to return to a normal life but later engaged in advocacy and awareness efforts related to AVMs.

Treatment options and recovery outcomes further demonstrated differences between patient responses to diagnoses (Table 3). Participants underwent varied procedures, including sclerotherapy (Participant 1), emergency surgery (Participant 6), advanced interventions like gamma knife radiation (Participant 2 and Participant 5), embolization to block blood flow to the AVM, and microsurgical resection for complete removal. Recovery experiences ranged from Participant 2 and Participant 5 re-learning motor skills and coping with cognitive challenges to Participant 3 and Participant 1 managing more gradual lifestyle adjustments.

Coping strategies were also diverse. Some participants relied heavily on online resources to learn about AVMs, such as Participant 2 and Participant 4, while others, like Participant 3 and Participant 5, prioritized consultations with medical experts. Advocacy emerged as a significant coping mechanism, with both Participant 2's and Participant 5's families playing active roles in raising awareness and supporting others affected by AVMs.

Overall, the findings reveal shared physical, emotional, and financial challenges among AVM patients, highlighting the profound impact of the condition on daily life. However, individual differences in diagnosis, socioeconomic context, and coping strategies underscore the need for personalized support systems. These findings also emphasize the importance of community and advocacy in addressing the broader challenges posed by AVMs.

Patient advocacy groups emerged as a crucial resource in bridging gaps in education, awareness, and support for individuals with AVMs. Organizations such as The Aneurysm and AVM Foundation (TAAF) play a varied role, providing accessible medical information, fostering community connections, funding research, and advocating for policy changes that benefit patients. In this study, TAAF's importance extended beyond general advocacy, as it directly facilitated participant recruitment, with three individuals learning about and enrolling in the research through the foundation's outreach channels. By connecting patients to both peer networks and medical expertise, advocacy groups can help reduce the isolation often experienced with rare conditions like AVMs and strengthen

the collective voice needed to advance treatment options and improve quality of life.

**Table 3:** This table outlines the diverse symptoms, diagnoses, AVM locations, and treatment options experienced by each participant. The variation in medical histories reflects the unpredictable nature of AVMs and the individual treatment paths participants followed, underscoring the need for earlier diagnosis and tailored care.

| Participant | Symptom | Diagnosis | Location of AVM | Treatment options |
|---|---|---|---|---|
| 1 | L calf pain | MRI / U/S | L leg | Sclerotherapy |
| 2 | Migraines, vision loss | Embolization/ resection | Brain | Resection, gamma knife, embolization + resection |
| 3 | Peripheral blurry vision, confusion/anxiety, tingling in hand | CT scan | Brain | Embolization-craniotomy |
| 4 | Worst headache of life, vomiting, passing out | Stroke/brain bleed | Brain | Surgery |
| 5 | Worst headache, stroke/brain bleed | Stroke/brain bleed | Brain | EVD to drain spinal fluid - angiograms, gamma knife radiation (3), chemo, craniotomy |
| 6 | Headaches, body aches | Stroke/brain bleed | Brain | Emergency surgery - no options |

This study provides a unique perspective on the lived experiences of patients with arteriovenous malformations (AVMs), contributing to the narrow selection of research about patient-centered outcomes in AVM care. While most existing studies have a clinical focus, this work emphasizes the social, emotional, and economic impacts of AVMs by focusing on how patients navigate diagnosis, treatment, and recovery. The data collected from six participants highlights key trends, identifies disparities, and highlights the need for systemic improvements in AVM care and policy.

***Demographics and Comparisons to US AVM Populations:***

The demographics of this study's participants—diversity in age, gender, and socioeconomic background reflect patterns observed in broader US AVM populations. Previous research, such as the Columbia Presbyterian Medical Center AVM Study, indicates that AVMs are disproportionately diagnosed among white individuals, with underrepresentation of Black, Hispanic, and Asian populations (70%, 9%, 13%, and 4%, respectively).[14] Other studies have corroborated these findings, suggesting that racial disparities in AVM diagnosis may stem from systemic factors such as unequal access to healthcare, socioeconomic barriers, and diagnostic bias.[15] Research on neurological disorders, including stroke and other cerebrovascular anomalies, has shown that Black and Hispanic populations are often diagnosed later or at more advanced stages due to disparities in medical access and provider biases.[16] The current study, although small in size, offered perspectives from some underrepresented groups in national datasets, including a white woman, a Hispanic woman, two white men, an Asian man, and an Indian woman. Additionally, this study included participants from rural, suburban, and urban locations, acknowledging geographic diversity as a crucial factor in AVM healthcare access and outcomes. However, the limited sample size restricts the ability to draw absolute conclusions about racial or ethnic disparities compared to national findings identified in larger studies like the Columbia Presbyterian Medical Center AVM Study and subsequent national registry data.

***Expected vs. Observed Trends:***

Comparing expected trends from larger databases to the observed trends in this study highlights important patterns and gaps in AVM diagnosis and treatment. National data, such as findings from the UCSF AVM Study Group, indicate a significantly greater risk of AVM hemorrhage among U.S. Hispanic individuals compared to whites.[17] This trend was reflected in the current study, as the Hispanic participant experienced an AVM rupture requiring emergency intervention. Her experience aligns with the broader observation of increased hemorrhage risk but also highlights the challenges of navigating treatment from a rural area with limited access to specialized care. These challenges reflect broader themes found in research on rural-urban health disparities, which suggest that differences in access and use of health information sources may be influenced by sociodemographic factors. Structural barriers, such as a shortage of specialist doctors and limited media exposure, can make it more difficult for rural residents to access critical health information, potentially delaying diagnoses and treatment.[18]

This study was descriptive and not intended to test racial or ethnic disparities formally, so any findings regarding these disparities should be interpreted cautiously as exploratory. Nevertheless, it highlights disparities in access to care based on geography, socioeconomic status, and race, emphasizing how these factors influence patient outcomes and experiences. While the small sample size prevents definitive conclusions, the concordance between certain participant anecdotal experiences with national trends— such as higher hemorrhage risks for Hispanic individuals and the travel-related challenges faced by rural patients—offers beneficial insights.

***Gender, Location, and Socioeconomic Factors:***

Gender and geographic location played a significant role in shaping participants' medical experiences. Male participants were more likely to undergo intensive medical interventions, such as multiple surgeries and therapies, whereas female participants reported making more lifestyle-oriented adjustments after treatment. This trend aligns with insights from Stanford Medicine Magazine's article, Two Minds: The Cognitive Differences Between Men and Women, which examines how biological sex differences influence cognitive function, memory, and emotional processing, emphasizing the impact of neurological and physiological variations on behavior and experiences.[19]

In addition, rural participants faced significant travel barriers and financial strain, whereas urban participants benefited from proximity to advanced medical centers and better insurance support. These disparities highlight the challenges faced by rural patients and emphasize the need for equitable healthcare access.

The findings from this study point to several potential policies and economic interventions. For example, insurance

companies could be required to cover travel-related costs for patients in rural areas, ensuring that financial barriers do not limit access to specialized care. Public health policies should also prioritize improving healthcare infrastructure in rural regions, reducing the need for extensive travel. For example, ensuring every patient can reach a major medical center within 60 minutes could dramatically improve outcomes.

Guidelines should be established for managing AVMs nationally, including recommendations for hospital stays following strokes or ruptures. While guidelines for AVM management do exist, such as those from the American Heart Association and American Stroke Association (AHA/ASA), implementing nationwide policy changes remains challenging due to the lack of universal healthcare coverage in the U.S. These guidelines could help address variability in care and provide a benchmark for hospitals nationwide. This study is one of the few to focus on the patient experience with AVMs, but it has limitations. The small sample size of six participants restricts the generalizability of the findings.

Since low-income individuals may have been underrepresented due to the time constraints of their work and family responsibilities to participate in the interview process, the study could reflect a socioeconomic bias. Future studies could address this by using targeted recruitment methods to guarantee a representative sample. A follow-up study focusing on a single racial or ethnic group could provide valuable insights into how cultural and systemic factors influence AVM care and outcomes. Expanding the sample size and conducting longitudinal studies could also help identify long-term trends and differences in recovery courses.

Finally, data collection methods had to be altered for participants with speech impediments, and participants' boundaries had to be respected when discussing personal medical experiences. These changes may have affected the data. Additionally, while flexible, the online interview format relative to in-person interviews has limited non-verbal observations, such as body language, fluency, eye contact, and appearance, potentially impacting the data's depth.

## Conclusion

Unlike most AVM studies that emphasize clinical outcomes, this research highlights the social, emotional, and economic impacts of AVMs, showing how patients navigate diagnosis, treatment, and recovery. Participants included a mix of genders, ethnicities (white, Hispanic, Asian, Indian), and geographic locations (urban, suburban, rural). Though small, the study captured perspectives from groups often underrepresented in national datasets. Rural participants experienced significant barriers in accessing specialized care, echoing broader rural-urban health disparities. The study underscored the role of geography, race, and socioeconomic status in shaping diagnosis and outcomes. Male participants were more likely to undergo intensive interventions, while female participants made more lifestyle-focused adjustments after treatment. Rural patients faced major travel and financial burdens, while urban patients benefited from better access to advanced medical centers and insurance support. In addition, it was found that four out of 6 participants were initially misdiagnosed, and one participant's AVM was not detected until they were in critical care when their AVM hemorrhaged due to the lack of awareness in the medical field. These findings suggest that future research should explore the socioeconomic and racial/ethnic disparities in AVM care with a larger, population-representative sample. For example, additional work such as larger and more diverse samples and targeted studies on specific racial or ethnic groups could provide deeper insights into AVM disparities and recovery outcomes. Specifically, these changes could help investigate the barriers to early diagnosis and lead to the development of interventions to reduce diagnostic delays. For instance, increasing awareness among primary care providers about AVM symptoms could improve early detection.

At a policy level, economic incentives for rural healthcare development and expanded insurance coverage for AVM-related care could reduce disparities in healthcare access based on geographic location. To ensure that all patients, regardless of location or income, receive timely and effective care, advocacy groups and healthcare organizations should collaborate to raise awareness about AVMs.

In conclusion, this study sheds light on the lived experiences of AVM patients, highlighting shared challenges and systemic inequities. Addressing these issues through targeted research, policy reforms, and healthcare interventions has the potential to improve outcomes and quality of life for AVM patients nationwide.

## Acknowledgments

I thank Carin Papendorp for guiding and supporting me throughout this project.

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DOI: 10.36838/IJHSR84.1