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# Improving Access to High-Quality Sarcoma Care: Practical Delivery Models to Reduce Delays, Disparities, and Financial Toxicity

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## Abstract

Sarcomas are rare malignancies encompassing more than 100 histologic subtypes. Their complexity demands specialized and multidisciplinary expertise that is difficult for many patients to access. Diagnostic delays, structural disparities, and significant financial toxicity collectively impede timely and attainable access to high-quality care.

This narrative review synthesizes published literature on barriers to high-quality sarcoma care delivery and evaluates emerging solutions designed to address them, including hub-and-spoke networks, coordinated specialist review panels, telemedicine, and community provider education. Relevant publications were identified through PubMed and Google Scholar searches; epidemiologic data was drawn from publicly available national databases including the National Cancer Institute Surveillance, Epidemiology, and End Results Program (SEER) and the National Cancer Institute National Childhood Cancer Registry (NCCR).

Meaningful improvement in sarcoma outcomes will require not only therapeutic advances, but also a deliberate redesign of how care is delivered: standardized referral pathways, expanded multidisciplinary infrastructure, and improved support to receive specialized expertise. As a rare and heterogeneous disease, sarcoma offers a valuable perspective towards the broader challenges in oncologic care delivery.

## Take-Home Messages

1. Diagnostic delays in sarcoma exist at the patient, provider, and system level. Potential solutions include standardized referral pathways and broader awareness of red flag symptoms among community providers.
2. Geographic, racial/ethnic, and age-related disparities contribute to inequities in how sarcoma expertise is distributed, not simply differences in disease biology.
3. Hub-and-spoke networks, telemedicine, and remote pathology review show conceptual promise, but lack prospective outcome data in sarcoma, representing a critical gap for future research.
4. Financial toxicity remains a significant barrier that disproportionately affects low-income and rural patients.
5. Sarcoma's rarity and complexity make it a compelling model for designing and testing care delivery innovations applicable across oncology.

## Introduction

Sarcomas are rare malignancies of mesenchymal origin, encompassing more than 100 histologic subtypes that can arise in virtually any anatomic location, explaining their broad molecular and clinical heterogeneity.[1] While some subtypes are driven by specific chromosomal translocations, such as the EWSR1-FLI1 fusion in Ewing sarcoma,[2] others harbor complex genomic backgrounds without a single identifiable driver. In addition, the different subtypes of sarcoma express a wide range of clinical behavior from indolence and locally confined boundaries to highly aggressive with early metastatic potential. Their treatment sensitivity to chemotherapy also varies considerably across subtypes.[3] This diversity makes sarcoma diagnostically and therapeutically challenging in clinical practice, fundamentally limiting the familiarity that generalist and community providers have.

Optimal management requires coordinated input from many departments, including surgical, medical, and radiation oncology, pathology, radiology, rehabilitation, and supportive care.[4] Current studies have supported centralized, expert care. Implementation of a nationwide network of sarcoma reference centers in France was associated with improved survival and increased compliance with clinical practice guidelines over a ten-year period.[5] Yet despite this evidence, only 17% of patients with soft tissue sarcoma receive care at high-volume facilities.[6] As shown in Table 1, sarcoma incidence in the United States has increased significantly between 2013 and 2022,[7] highlighting the growing number of patients that are being diagnosed within a system not yet adequately structured to serve them.

The consequences of this are well-documented. Patients with sarcoma face prolonged diagnostic delays at patient, provider, and system levels.[8] Geographic location, race and ethnicity, socioeconomic status, and age all influence whether and how quickly a patient reaches specialized care.[9] Financial toxicity compounds these barriers.[10] Together, these challenges produce an environment where outcomes are not shaped only by tumor biology, but by where a patient lives, who their doctor is, and what they can afford.

This narrative review examines key barriers to high-quality sarcoma care delivery and evaluates emerging solutions designed to address them, including hub-and-spoke networks, telemedicine, remote pathology review, and community provider education. We also consider why sarcoma specifically can serve as a valuable model for care delivery innovation within oncology. The review is organized across four sections: diagnostic delays and referral fragmentation, disparities in access and outcomes, innovative solution models, and financial toxicity.

## Methods

This article summarizes published literature on barriers to sarcoma care delivery, including diagnostic delays, access to care disparities, financial toxicity, and novel proposals designed to address them. Relevant publications were found through searches using PubMed and Google Scholar between March and May 2025. Search terms included combinations of "sarcoma," "patient care access," "delay," "health disparities," "financial toxicity," "barriers," "telemedicine," and "care coordination." No language restrictions were applied. Publications from 2010 onward were considered, with priority given to studies published from 2020 onward, large population-based analyses, and publications that had direct relevance to sarcoma care delivery. Addi-

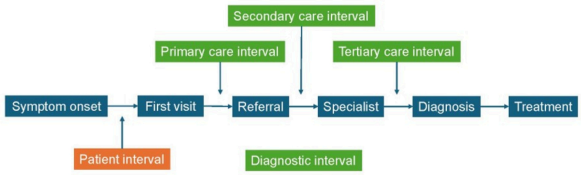
*Table 1. Soft Tissue including Heart trends in Delay-Adjusted SEER Incidence average annual percent change between 2013-2022. Data derived from National Cancer Institute Surveillance, Epidemiology, and End Results Program (2013-2022). 7*

| Year Range | Average Annual Percent Change (%) | Lower 95% C. I. | Upper 95% C. I. | P-Value | Direction |
|---|---|---|---|---|---|
| 2013-2022 | 0.7 | 0.4 | 0.9 | <0.01 | Rising |
| 2018-2022 | 0.7 | 0.4 | 0.9 | 0.02 | Rising |

tional sources were also identified through reference list review and expert recommendation. Epidemiologic data were drawn from publicly available national databases, including the National Cancer Institute Surveillance, Epidemiology, and End Results Program (SEER) and the National Childhood Cancer Registry (NCCR).

## Diagnostic Delays and Fragmented Referral Pathways

Timely diagnosis is critical in sarcoma care but is often complicated by its rarity and heterogeneous clinical presentation. As illustrated in **Figure 1**, delays may occur across multiple stages of the diagnostic pathway: the patient interval, outlining symptom onset to initial clinical guidance, through primary, secondary, and tertiary care intervals before a definitive diagnosis is reached. Each stage represents both a source of delay and an opportunity for intervention.




### Patient-Level Delays

Patient-level delays often arise because sarcomas typically present with nonspecific symptoms that are easily mistaken for benign conditions. In the early stages of some sarcomas, there may be few signs. Then, as the soft tissue mass grows, presentations can mimic trauma or sports injuries. One study found that misdiagnosis commonly occurred when symptoms were attributed to active lifestyles, like participating in kickboxing.[11] Because of this difficulty to recognize severity, patients struggle to know when to seek clinical support. Another study found that the median patient interval from symptom onset to seeking clinical evaluation was approximately 90 weeks, exceeding the diagnostic interval itself.[8]

### Provider-Level Delays

Provider-level delays are also common because sarcomas are not typically encountered in routine clinical practice. Many primary care physicians and community specialists may see few, if any, sarcoma cases during their careers, limiting familiarity with appropriate diagnostic pathways.[12] Consequently, concerning lesions may initially be monitored, treated conservatively, or evaluated without appropriate imaging and tissue diagnosis. Key clinical symptoms that should prompt specialist referral, along with current National Comprehensive Cancer Network (NCCN) guidelines, are outlined in Table 3.

### Consequences of Diagnostic Fragmentation

One important consequence of diagnostic delays is the occurrence of an unplanned excision, commonly known as a "whoops" surgery. During these procedures, a soft tissue sarcoma is resected under the assumption that it is benign, often without appropriate imaging, biopsy, or multidisciplinary review. While the clinical impact of these unplanned resections has not been conclusively studied, a target trial emulation found local recurrence rates were higher among patients who underwent unplanned excisions (24.5%) compared to those who underwent planned resections (17.3%).[13] These findings suggest that creating an infrastructure to resolve these delays will not only allow patients to be diagnosed faster, but also prevent unintended and inappropriate treatments.

## Disparities in Sarcoma Outcomes

*Table 2. 5-Year relative survival rates of U.S. children, adolescents, and young adult sarcoma patients. Data obtained from National Cancer Institute National Childhood Cancer Registry Explorer (2015-2021). 16*

| Age | 5-Year Relative Survival (%) | Lower 95% C.I. | Upper 95% C.I. |
|---|---|---|---|
| Age <1 | 72 | 65.7 | 77.4 |
| Ages 1-4 | 79.5 | 75.9 | 82.6 |
| Ages 5-9 | 76.1 | 71.9 | 79.9 |
| Ages 10-14 | 73.6 | 70.3 | 76.5 |
| Ages 15-19 | 73.8 | 71 | 76.3 |
| Ages 20-24 | 69.3 | 66.7 | 71.8 |
| Ages 25-29 | 72.4 | 70.3 | 74.4 |
| Ages 30-39 | 73.9 | 72.6 | 75.1 |

Beyond diagnostic delays, patients face disparities across multiple dimensions: geographic, structural, racial and ethnic, and age-related. These disparities can influence not only when a patient receives care, but also the location, accessibility, and quality of care available to them.

## Geographic and Institutional Disparities

Geographic location is a significant determinant of sarcoma outcomes. In a large population-based cohort, 5-year cause-specific survival was lowest among patients in rural areas (68.9%) compared to urban (70.0%) and metropolitan regions (71.6%) ($p < 0.001$).[9] These differences suggest an unequal distribution of sarcoma expertise with rural patients facing a greater travel burden, limited access to imaging, and fewer opportunities for multidisciplinary evaluation.

Access to high-volume centers compounds this disparity. In a study of 9,025 patients, only 17% received care at high-volume sarcoma facilities, while the remaining 83% were treated at low-volume centers—despite high-volume care being associated with significantly improved overall survival ($p = 0.001$).[6] The survival benefit at specialized centers likely reflects the availability of specialized expertise, subspecialty pathology review, sarcoma-focused surgical teams, and clinical trials. Despite these benefits, these high-volume centers are underutilized by most of the sarcoma population, showing the difficulty patients face reaching these geographically concentrated centers.

## Racial and Ethnic Disparities

Racial and ethnic disparities also contribute to differences in sarcoma outcomes. As seen in **Figure 2**, mortality-to-incidence ratios are higher among Black individuals compared to White, Hispanic, and Asian populations, indicating worse survival following diagnosis rather than differences in disease occurrence. The mechanisms underlying these disparities are likely multifaceted with potential contributors including differences in access to specialized care, socioeconomic barriers, insurance coverage, and broader structural inequities within healthcare systems.

## Adolescent and Young Adult (AYA) Sarcoma Care

Disparities are also observed among adolescent and young adult (AYA) patients, a population that frequently falls between pediatric and adult oncology systems.[14] Although typically treated within adult oncology settings, evidence suggests that some AYA sarcoma patients may benefit from treatment approaches more commonly used in pediatric oncology. A study found that adolescents (aged 15-19) with soft tissue sarcoma have worse survival rates than children, attributing this gap partly to the lack of access to AYA expert centers.[15]

Table 2 further highlights this disparity, with patients aged 20–24 years experiencing the lowest 5-year relative survival rate compared to pediatric, adolescent, and other young adult age groups.[16] These findings reflect gaps in care coordination, differences in clinical trial enrollment, and limited

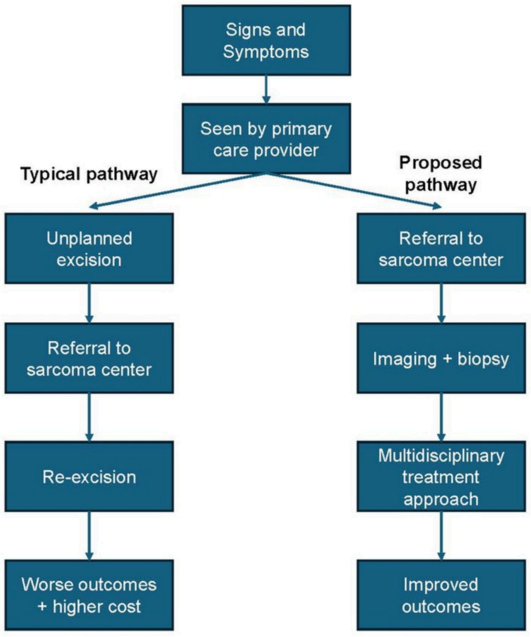
*Table 3. Red Flag Clinical Features Referral Triggers for Soft Tissue Sarcoma 4, 22*

| **Clinical Feature** |
|---|
| Soft tissue mass ≥ 5cm |
| Deep fascial location |
| Progressive enlargement |
| Present without any explanation |
| Axial location (trunk/proximal limb/pelvis) |
| Pain at rest or night |

specialization for patients transitioning between pediatric and adult oncology settings. Only 3-14% of AYA patients were found to enroll in clinical trials nationwide.[17] Improved collaboration between pediatric and adult sarcoma programs may help address these challenges and ensure that AYA patients receive coordinated, multidisciplinary care throughout diagnosis, treatment, and survivorship.

## Centralization of Sarcoma Care and Emerging Delivery Models

Given the diagnostic delays, disparities, and fragmented referral pathways described above, **Figure 3** illustrates a standardized pathway designed to efficiently and effectively diagnose and treat sarcoma patients. The other models described in this section are designed to build upon this framework, expanding access to specialized expertise while minimizing geographic, travel, and healthcare barriers.




### Hub-and-Spoke Models and Shared-Care Approaches

The development of hub-and-spoke networks, connecting high-volume sarcoma centers with community oncology practices or regional healthcare systems, could centralize complex case management at specialized facilities while allowing peripheral sites to manage routine treatment delivery closer to patients' homes.[18] For example, systemic therapy administration, routine imaging, and supportive care may be coordinated through local treatment teams while sarcoma specialists maintain oversight. One instance of this hub-and-spoke model in action was studied at the O'Neal Cancer Center at the University of Alabama at Birmingham and its rural affiliate hospital, Russell Medical Center. Despite the 70-mile distance, cancer center surgeons operating at the rural affiliate showed comparable peri-

operative outcomes and guideline-concordant care for patients with non-metastatic breast cancer.[19] This supports the potential of these networks to optimize resource use and improve quality of care, while reducing travel burden for geographically disadvantaged patients.

### Multidisciplinary Review and Virtual Tumor Boards

Another strategy to improve sarcoma outcomes is multidisciplinary evaluation. A study found that presentation at a specialized tumor board before treatment has been independently associated with improved relapse-free survival.[5] With the utilization of technology and hub-and-spoke networks, virtual tumor boards have the potential to extend expertise beyond their traditional in-person clinic. This would allow specialists in surgical, medical, and radiation oncology, pathology, and radiology to collaboratively make treatment decisions regardless of where they or a patient is located.

### Remote Pathology Review and Diagnostic Support

Accurate pathologic diagnosis is one of the most critical steps for appropriate sarcoma management; however, diagnostic inconsistency between non-specialist and expert pathologists is well-documented. Studies have reported discordance rates ranging from 38% to nearly 60% when sarcoma diagnoses made at non-specialist centers are reviewed by dedicated sarcoma pathologists. Major discordance, defined as a change in diagnosis or treatment management, is associated with reduced overall survival.[20, 21] These findings highlight the importance of expert pathology review in the diagnostic workflow. Remote pathology review and digital pathology platforms are an easy way to extend expertise, improve diagnostic accuracy, and help prevent inappropriate treatments.

Provider awareness of common clinical features of sarcoma also represents an important part of the diagnostic pathway. With improved recognition of red flag clinical features and adherence to NCCN-recommended imaging and biopsy timelines (Table 3), providers will be able to know when it is appropriate to seek sarcoma expertise.

### Coordinated Care for Adolescent and Young Adult Patients

Because AYA patients frequently transition between pediatric and adult oncology systems, seamless care coordination is imperative for this population. Collaboration with both pediatric and adult sarcoma specialists can help facilitate appropriate planning, survivorship care, and clinical trial enrollment. Tools such as Passport for Care, a web-based platform that tracks individual treatment exposures, demonstrate how standardized documentation can improve care continuity during these transitions by ensuring critical clinical information is accessible across multiple healthcare settings.[23]

### Expanding Geographic Access Through Telemedicine and Digital Health

Telemedicine also offers new opportunities to improve access to specialized sarcoma care. Virtual consultations can help facilitate earlier referrals, second opinions, multidisciplinary review, and long-term follow-up, all while reducing travel burdens. In one study, 75% of scheduled appointments were successfully converted to telemedicine with high patient satisfaction and no increase in clinician workload. 80% of patients requested that telemedicine be part of their future care plans, citing the reduced cost and travel time as a significant reason.[24]

When integrated into proposed hub-and-spoke models, telemedicine can also help connect local providers with specialty centers, allowing them to collaborate throughout the patient's journey. Telemedicine is best suited for consultative and surveillance visits that do not require physical examination, biopsy, or surgical intervention.

### System-Level Interventions to Address Racial Disparities

In a pragmatic trial across five cancer centers, a multifaceted intervention helped reduce the Black-White treatment gap in early-stage lung cancer. These features included race-specific outcome feedback to clinical teams, an automated EHR-based alert system for missed appointments, and nurse navigators who re-engaged patients and resolved barriers to their care. These interventions meaningfully improved care for both Black and White patients—27% and 17% respectively—relative to historical baselines.[25] This study offers a transferable framework for addressing treatment disparities across other cancer types.

## Financial Toxicity in Sarcoma Care

Financial toxicity is a significant challenge in sarcoma care. Because specialized sarcoma services are concentrated at specific referral centers, many patients face substantial nonmedical expenses, like travel, lodging, lost wages, and caregiver burden, in addition to direct treatment costs. This burden disproportionately impacts rural and low-income patients, for whom the same centralization of sarcoma care that helps improve clinical outcomes also creates the greatest financial strain. For AYA patients specifically, fertility preservation prior to systemic therapy represents an additional and often uncovered expense, with the average cost of oocyte cryopreservation exceeding $10,000 and insurance coverage remaining inconsistent across states.[26] In addition, insurance denials for imaging, provider consultations, and novel treatments further compound these burdens. A 2025 survey found that 95% of physicians report prior authorization causing care delays, with more than 25% reporting an associated serious adverse event for a patient in their care.[27]

In terms of treatment, sarcoma-specific therapies add substantially to financial burdens. Sarcoma care average costs have been reported to exceed $28,000 per month.[10] In addition, data has found that per-patient annual cancer care costs vary significantly across phases of care—peaking at diagnosis and end of life—and can approach or exceed average individual wages in the United States.[28, 29] For sarcoma patients, this metric is likely compounded given the complexity of sarcoma treatment, need for specialized surgical care, and longer treatment trajectories associated with recurrent or metastatic disease.

Several resources and interventions can help alleviate financial burdens for sarcoma patients. Organizations such as the Sarcoma Alliance, the National Organization for Rare Disorders, and the NCCN Virtual Reimbursement Resource Room offer financial assistance, patient support programs, and guidance on insurance navigation.[30, 31, 32] Financial navigation services, which dedicate navigators to resolve insurance issues and reduce out-of-pocket costs, have demonstrated significant intervention effectiveness in cancer patients.[33] Participation in clinical trials may also provide reimbursement for certain treatment-related costs. Integrating these resources into routine sarcoma care, particularly at the point of diagnosis, may ultimately help reduce the economic strain that often compounds the clinical burden of this disease.

## Discussion

This narrative review synthesizes evidence on barriers to sarcoma care delivery and evaluates solutions designed to address them. Among diagnostic delays, geographic and structural disparities, racial and ethnic inequities, AYA-specific challenges, and financial toxicity, the consequences of fragmented care connect them all. Each of these problems contribute to worse sarcoma outcomes in ways that are largely preventable.

Standardized referral pathways and improved recognition of red flag symptoms among community providers will improve accurate diagnoses. Multi-institutional collaboration will also be essential to evaluating emerging models and identifying best practices at scale.

The centralization of sarcoma expertise at high-volume centers has demonstrated survival benefits, yet most patients still receive care outside of these settings. Innovative delivery models, like hub-and-spoke networks, virtual tumor boards, and telemedicine, can offer alternative and promising frameworks that extend expertise without overburdening patients.

Finally, financial toxicity may be alleviated through policy interventions like insurance authorization reform, expanded fertility preservation insurance mandates, and reimbursement frameworks.

Several limitations of this review should be acknowledged. As a narrative review, it is subject to selection bias in the literature reviewed and does not employ systematic methods for study inclusion or quality assessment. Many of the delivery models discussed are supported primarily by conceptual frameworks and limited observational data rather than prospective trials. Much of the available evidence on sarcoma disparities derives from retrospective analyses and administrative datasets, which may not fully capture the complexity of access barriers. Finally, the generalizability of findings from international sarcoma networks,

like the European model NETSARC, to the United States healthcare context should be interpreted with caution given differences in healthcare system structure.

## Conclusion

Sarcoma care delivery is shaped not only by tumor biology but by where patients live, who their providers are, and what they can afford. Meaningful progress towards improved access to high-quality sarcoma care will require deliberate and extensive redesign of how sarcoma care is organized and delivered. Standardized referral pathways, hub-and-spoke networks, and community provider education offer practical solutions for extending specialized care to local regions, though prospective evidence evaluating their impact remains critical.

As a rare and heterogenous disease with well-documented care delivery failures, sarcoma provides a compelling model for examining and addressing broader challenges in oncologic care delivery. The insights gained from improving sarcoma care infrastructure have the potential to help revolutionize care delivery across more rare and complex cancers.

## Conflict(s) of Interest

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## Ethical Statements

N/A. This review involved no primary data collection from human participants.

## Informed Consent

N/A. This review involved no primary data collection from human participants.

## Data Availability Statement

N/A. No new data were generated or analyzed in this study.

## Declaration of AI Use in Scientific Writing

During the preparation of this review article, the authors used Claude (Anthropic) and ChatGPT (OpenAI) to assist with language refinement and manuscript organization. All final decisions regarding content, interpretation, and accuracy were made by authors who also reviewed, edited, and verified all content.

## Author Contributions

Concept and design: VM, CY
Data acquisition: VM, CY
Data analysis and interpretation: VM, CY
Drafting of the manuscript: VM, CY
Critical revision of the manuscript: VM, CY
All authors (VM, CY) approved the final version of the manuscript and agree to be accountable for all aspects of the work, in accordance with the International Committee of Medical Journal Editors criteria.

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