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Inequities in Access to Pediatric Cancer Care: Evidence from Underserved Populations

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ABSTRACT

Childhood cancer remains a leading cause of disease-related mortality among children and adolescents despite significant improvements in survival. This study summarizes major barriers affecting access to pediatric cancer care among underserved populations. A narrative review of peer-reviewed studies was conducted using PubMed, Scopus, and Google Scholar. Studies examining structural, socioeconomic, geographic, and healthcare system barriers affecting pediatric cancer diagnosis, treatment access, or continuity of care were included. Findings were synthesized to identify common determinants influencing access to pediatric oncology services. Leukemia accounted for approximately 28–30% of pediatric cancers, followed by brain and central nervous system tumors (25–27%) and lymphomas (10–12%). Approximately 15–20% of children in the United States live in rural areas with limited access to specialized pediatric oncology services. Reported diagnostic intervals ranged from 4 to 12 weeks from symptom onset to confirmed diagnosis. Families in rural regions frequently traveled more than 100 miles to reach tertiary pediatric oncology centers. Treatment duration for acute lymphoblastic leukemia commonly extends 2–3 years, contributing to financial and caregiving burdens. Structural healthcare limitations, geographic distance, and socioeconomic constraints remain key barriers to pediatric cancer care. Improving referral pathways, expanding access to specialized oncology centers, and strengthening supportive services may help reduce disparities in pediatric oncology care.

1. Introduction

Childhood cancer remains a significant global health challenge and continues to be one of the leading causes of disease-related mortality among children and adolescents. The most commonly diagnosed pediatric cancers include leukemias, tumors of the brain and central nervous system, lymphomas, neuroblastoma, Wilms tumor, osteosarcoma, and soft tissue sarcomas [1]. Among these, acute lymphoblastic leukemia (ALL) is the most frequently occurring diagnosis worldwide, accounting for a substantial share of pediatric cancer cases [2]. Over the past several decades, advances in treatment, such as combination chemotherapy, refined surgical approaches, targeted therapies, and improved supportive care, have led to remarkable improvements in outcomes. In high-income countries, five-year survival rates for childhood cancers now approach or exceed 80%, reflecting substantial progress in pediatric oncology [3].

Despite these gains, childhood cancer is still characterized by complex biological mechanisms and significant long-term health implications. Unlike many adult cancers, pediatric malignancies are less commonly linked to lifestyle factors and are more often associated with genetic predisposition, developmental processes, and early-life environmental exposures [4]. Certain genetic conditions, including RB1 mutations, Li-Fraumeni syndrome, and neurofibromatosis type 1, are strongly linked to an increased risk of developing childhood cancers. Moreover, exposure to treatments such as chemotherapy and radiotherapy can contribute to late effects, including an elevated risk of secondary malignancies later in life [5]. Evidence suggests that survivors of childhood cancer face a markedly higher risk of subsequent malignant neoplasms compared with the general population, underscoring the importance of long-term follow-up and survivorship care.

At the same time, disparities in access to timely diagnosis, specialized treatment, and supportive oncology services remain a critical public health concern. Children from underserved populations, particularly those in rural areas, low-income settings, or minority communities, often face structural barriers that delay diagnosis and limit access to high-quality care [6]. Pediatric cancer treatment typically requires coordination across specialized tertiary care centers, multidisciplinary teams, and advanced diagnostic resources. For many families, navigating this complex system can be challenging, with barriers such as long travel distances, transportation difficulties, financial strain, and a shortage of pediatric oncology specialists [7].

Beyond structural challenges, social determinants of health play an important role in shaping outcomes for children with cancer. Families facing socioeconomic disadvantage often deal with added pressures, including the cost of travel, temporary housing near treatment centers, and the demands of long-term caregiving [8]. Language barriers and limited health literacy can make it harder for families to understand treatment options and communicate effectively with healthcare providers. These challenges can affect how quickly a child is diagnosed, how well treatment plans are followed, and whether families are able to take part in clinical trials, all of which are critical for improving outcomes in pediatric oncology care [9].

These factors often overlap and create additional difficulties for families already navigating a complex healthcare system. When financial strain, communication barriers, and limited access to resources occur together, they can delay care and reduce the quality of support children receive throughout treatment. Understanding how these social and systemic factors interact is essential for identifying gaps in care and improving access for underserved populations.

The aim of this study is to examine the key barriers affecting access to pediatric cancer care among underserved populations. Specifically, the study seeks to identify major structural, socioeconomic, and healthcare system challenges that influence timely diagnosis, access to specialized treatment, and continuity of care. By bringing these factors together, this review aims to provide a clearer understanding of where disparities exist and to highlight areas where targeted interventions can help improve equity in pediatric oncology care.

2. Literature Review

Previous studies have identified several important factors that influence pediatric cancer outcomes, including socioeconomic status, geographic distance to specialized treatment centers, and the availability of health system resources [10]. These factors are consistently linked to differences in access to timely diagnosis and quality care. However, much of the literature has examined them separately, often focusing on a single issue such as insurance coverage, rural residence, or delays in diagnosis. While these studies provide valuable insights, they do not fully capture how multiple barriers combine and shape access to pediatric oncology care in real-world settings [11].

In practice, these challenges rarely occur in isolation. Families often face overlapping difficulties that make care more complex and harder to access. For example, living far from a treatment center can increase travel costs, disrupt family routines, and delay care. At the same time, limited financial resources or insurance coverage can further restrict access to specialists and timely treatment. Despite this, relatively few studies have taken a broader view to understand how structural barriers, health system limitations, and social conditions work together to influence care pathways for children with cancer.

Another important gap in the literature is the strong focus on clinical outcomes rather than care experiences. Much of the existing evidence comes from clinical registries and survivorship studies, which mainly report survival rates and treatment results. These are important, but they often overlook the challenges families face while navigating the healthcare system. As a result, there is still limited understanding of how underserved families manage the process of seeking diagnosis, accessing specialized services, and continuing care over time[12]. Addressing this gap requires a more integrated approach that brings together structural, socioeconomic, and healthcare system perspectives to better understand where barriers exist and how they can be reduced.

3. Methodology

3.1 Study Design

This study was conducted as a narrative synthesis of published literature examining barriers to pediatric cancer care among underserved populations. The goal of this approach was to bring together existing evidence on structural, socioeconomic, and healthcare system factors that influence timely diagnosis, treatment initiation, and continuity of care for children with cancer. A narrative synthesis was chosen because it allows for the integration of findings from a wide range of study designs, including epidemiologic studies, health services research, and observational investigations, providing a broader and more flexible understanding of the topic.

3.2 Literature Search Strategy

A targeted literature search was carried out to identify relevant studies on disparities and barriers in pediatric oncology care. Electronic databases, including PubMed, Scopus, and Google Scholar, were searched for peer-reviewed articles. The search strategy used combinations of keywords such as pediatric cancer, childhood oncology, health disparities, healthcare access, diagnostic delay, underserved populations, barriers to care, and pediatric oncology services. The search focused mainly on studies published within the past two decades to ensure the inclusion of up-to-date evidence on healthcare access and disparities. In addition, reference lists of selected articles were reviewed to identify other relevant studies addressing similar issues.

3.3 Study Selection Criteria

Studies were included if they examined barriers affecting access to pediatric cancer diagnosis, treatment, or supportive care. Eligible studies consisted of epidemiologic research, observational studies, health services analyses, and population-based investigations that explored structural, socioeconomic, geographic, or healthcare system factors influencing pediatric cancer care. Studies that focused primarily on biological mechanisms, molecular oncology, or treatment effectiveness without addressing healthcare access or disparities were excluded. Both U.S.-based and international studies were included to capture a wider perspective on access-related challenges in pediatric oncology care.

Titles and abstracts were first screened to assess their relevance to the study objectives. Articles that met the inclusion criteria were then reviewed in full to confirm their suitability for inclusion in the analysis.

3.4 Data Extraction

Key information was extracted from the selected studies to summarize findings related to barriers in pediatric cancer care. This included details such as study setting, characteristics of the study population, types of barriers identified, and their reported impact on diagnosis, treatment initiation, and continuity of care. Particular attention was given to studies that discussed delays in diagnosis, geographic challenges in accessing specialized oncology centers, financial burdens faced by families, insurance-related limitations, and communication barriers between families and healthcare providers.

3.5 Data Synthesis and Analysis

The collected evidence was analyzed using a thematic synthesis approach. Barriers reported across studies were grouped into major categories based on recurring patterns. These included structural barriers within healthcare systems, socioeconomic challenges faced by families, geographic limitations related to distance from specialized treatment centers, and communication or health literacy barriers. Organizing the findings into these themes allowed for a clearer and more structured understanding of the key factors influencing access to pediatric oncology care among underserved populations.

4. Findings

Across the studies reviewed, several demographic patterns were consistently reported in populations affected by barriers to pediatric cancer care. Most studies included children and adolescents under 18 years of age diagnosed with common pediatric malignancies such as leukemia, brain and central nervous system tumors, lymphomas, and solid tumors, including neuroblastoma and sarcomas. In the United States, leukemia accounts for approximately 28–30% of pediatric cancer diagnoses, followed by brain and central nervous system tumors (about 25–27%) and lymphomas (10–12%) [13]. The reviewed studies frequently focused on children from medically underserved communities, including those living in rural areas, low-income households, and minority populations. Several studies also reported that families affected by these barriers often had lower household income levels, limited access to private insurance, and greater reliance on public insurance programs [14]. These demographic characteristics are closely linked to differences in access to timely diagnosis, availability of specialized pediatric oncology centers, and supportive cancer care services. Four major barriers consistently emerge in the literature: delays in diagnosis and referral to oncology specialists, geographic limitations in accessing tertiary treatment centers, socioeconomic burdens experienced by families during treatment, and communication or health literacy challenges when navigating complex healthcare systems.

Table 1. Summary of Demographic Characteristics & Major Barriers to Pediatric Cancer Care Identified in the Literature

Category	Key Findings	Reported Statistics / Evidence
Age Group	Most studies included pediatric patients diagnosed before age 18.	Pediatric cancer population defined as children and adolescents <18 years.
Common Cancer Types	Leukemia, brain and central nervous system tumors, lymphomas, and solid tumors (e.g., neuroblastoma, sarcoma) were most frequently reported.	Leukemia ~28–30% of cases; brain/CNS tumors ~25–27%; lymphomas ~10–12%.
Socioeconomic Characteristics	Families often from lower-income households with limited financial resources during treatment.	Higher reliance on public insurance programs (e.g., Medicaid) reported in several studies.
Geographic Distribution	Many affected families lived in rural or medically underserved areas with limited access to pediatric oncology centers.	Approximately 15–20% of U.S. children live in rural areas where access to specialized care may be limited.
Insurance Coverage	Public insurance or underinsurance frequently reported among underserved populations.	Greater dependence on Medicaid or other public programs in low-income families.
Structural Barriers	Limited availability of specialized pediatric oncology services and complex referral pathways.	Delays in referral to tertiary care centers reported in multiple studies.
Geographic Barriers	Long travel distances to tertiary pediatric oncology hospitals.	Families may travel >100 miles to reach specialized cancer centers.
Socioeconomic Burden	Indirect treatment costs including travel, housing, and lost wages.	Pediatric cancer treatments may extend 2–3 years for certain malignancies (e.g., ALL).
Communication Barriers	Health literacy limitations and language differences affecting care navigation.	Reported difficulties understanding treatment plans and follow-up care instructions.

Source: Research Data obtained from the selected literature [8-12]

Table 1 summarizes the key demographic characteristics and major barriers to pediatric cancer care identified across the reviewed literature. The table highlights common pediatric cancer types, population characteristics of affected families, and the major structural, socioeconomic, geographic, and communication-related challenges reported in previous studies. These findings provide an overview of the demographic context and key determinants that may influence access to timely diagnosis, specialized treatment centers, and supportive oncology services.

4.1 Diagnostic Delays and Referral Barriers

Multiple studies reported that delays in diagnosis remain a common challenge in pediatric oncology care. Pediatric cancers often present with nonspecific symptoms, which can contribute to delays in specialist referral. Epidemiologic data indicate that leukemia accounts for approximately 28–30% of pediatric cancers in the United States, followed by brain and central nervous system tumors (approximately 26%) and lymphomas (10–12%)[15]. Studies examining diagnostic intervals have reported that the median time from symptom onset to diagnosis can range from approximately 4 to 12 weeks depending on cancer type[16]. Research has also shown that children from underserved communities are more likely to experience prolonged diagnostic intervals, partly due to reduced access to pediatric specialists and limited familiarity of primary providers with early signs of malignancy[17].

4.2 Geographic Access to Specialized Pediatric Oncology Centers

Geographic distance from specialized treatment centers was consistently associated with barriers to care. Pediatric oncology services in the United States are highly centralized, with the majority of treatment delivered through large tertiary hospitals participating in cooperative research networks such as the Children's Oncology Group. Studies have reported that families living in rural areas may travel more than 100 miles to reach specialized pediatric oncology facilities [18]. Approximately 15–20% of U.S. children live in rural areas, and these populations may experience greater difficulty accessing specialized oncology services. Research examining treatment participation has shown that children residing farther from tertiary care centers are less likely to enroll in clinical trials, despite the fact that more than 60% of pediatric cancer patients in the United States participate in cooperative clinical research protocols [19].

4.3 Socioeconomic Burden During Pediatric Cancer Treatment

Socioeconomic constraints were another major determinant of access to care. Studies examining family experiences during pediatric cancer treatment report that families frequently face substantial indirect costs related to transportation, temporary housing near treatment centers, and lost income during prolonged caregiving periods [20]. Treatment for certain pediatric cancers, such as acute lymphoblastic leukemia, may extend for two to three years, creating long-term financial pressures for families. Research has shown that childhood cancer survivors also face elevated long-term health risks, including the development of subsequent malignant neoplasms. Studies estimate that survivors of childhood cancer have more than a tenfold higher risk of developing secondary malignancies compared with the general population, emphasizing the need for consistent long-term follow-up care[21].

4.4 Communication and Health Literacy Barriers

Communication barriers within healthcare systems were also identified across several studies. Caregivers may face difficulty understanding complex treatment protocols, medication schedules, and long-term monitoring recommendations. Studies examining survivorship outcomes report that many childhood cancer survivors experience ongoing concerns related to long-term health risks and quality of life[22]. For example, research involving young adult survivors of childhood cancer found that approximately 49% had already become parents, while the remaining survivors often expressed concerns regarding potential health risks for future children and long-term survivorship outcomes. These findings illustrate the broader informational challenges faced by families and survivors navigating the pediatric cancer care continuum [23].

Table 2. Major Barriers to Pediatric Cancer Care and Their Reported Impact on Outcomes

Barrier Category	Description	Reported Impact on Pediatric Cancer Care	Example Evidence / Indicators
Diagnostic and Referral Delays	Limited recognition of early cancer symptoms and delayed referral to pediatric oncology specialists.	Longer diagnostic intervals and delayed treatment initiation.	Diagnostic delays reported ranging from 4–12 weeks from symptom onset to confirmed diagnosis in some studies.
Geographic Access Barriers	Long travel distances to specialized pediatric oncology centers, particularly for rural families.	Reduced access to specialized treatment, lower clinical trial participation, and difficulty maintaining follow-up care.	Some families travel >100 miles to reach tertiary pediatric oncology centers.
Socioeconomic Constraints	Financial strain related to transportation, temporary housing, lost wages, and indirect treatment costs.	Increased treatment burden on families and potential interruptions in care continuity.	Treatment for cancers such as acute lymphoblastic leukemia may last 2–3 years, increasing long-term financial burden.
Insurance and Healthcare System Barriers	Reliance on public insurance programs and limited access to specialized pediatric oncology networks.	Delayed referrals and limited availability of specialized pediatric oncology services in underserved regions.	Higher reliance on Medicaid or public insurance among low-income families reported across studies.
Communication and Health Literacy Challenges	Difficulties understanding treatment protocols, medication schedules, and long-term follow-up requirements.	Reduced engagement with healthcare providers and challenges navigating complex treatment plans.	Caregivers frequently report challenges interpreting multiphase chemotherapy protocols and survivorship care plans.

Source: Research Data obtained from the selected literature [24-26]

Table 2 summarizes the major barriers affecting pediatric cancer care and their documented impact on access to diagnosis, treatment, and survivorship care. As shown in Table 2, structural limitations within healthcare systems, geographic distance to specialized treatment centers, socioeconomic burdens faced by families, and communication barriers frequently interact to influence care experiences among underserved pediatric cancer populations.

Overall, the findings indicate that barriers to pediatric cancer care are multifactorial and often interrelated. Structural limitations within healthcare systems, socioeconomic challenges faced by families, geographic distance to specialized pediatric oncology centers, and communication or health literacy barriers collectively influence access to timely diagnosis, treatment initiation, and continuity of care. These factors may contribute to disparities in pediatric cancer care, particularly among children from underserved communities, highlighting the importance of addressing systemic and social determinants to improve equitable access to pediatric oncology services [27].

4.5 Key Barriers to Pediatric Cancer Care and Their Impact on Outcomes

In the United States, pediatric cancers are relatively rare but remain a leading cause of disease-related mortality among children [28]. Leukemia accounts for approximately 28–30% of cases, followed by brain and central nervous system tumors (25–27%) and lymphomas (10–12%). Although survival rates in high-income countries now exceed 80%, these gains are not equally shared across all populations [29]. The findings of this review highlight persistent structural inequities, particularly delays in diagnosis, geographic barriers to specialized treatment, and financial burdens, which continue to shape disparities in pediatric oncology care [30]. Delays in diagnosis and referral remain a commonly reported challenge, as pediatric cancers often present with nonspecific symptoms that can be mistaken for routine childhood illnesses. Diagnostic intervals may extend from several weeks to months, depending on access to care [31]. Early detection is especially critical for aggressive cancers such as acute lymphoblastic leukemia and pediatric sarcomas. Additional biological considerations, including microbial dysbiosis and inflammatory processes, may further influence disease progression in some contexts [32]. Limited awareness among primary care providers, particularly in underserved or rural settings, may also contribute to delayed recognition and referral [33].

Geographic access to specialized pediatric oncology centers is another major determinant of care. In the United States, treatment is highly centralized within tertiary care institutions and cooperative research networks such as the Children's Oncology Group [19]. While this model has improved survival outcomes, it creates access challenges for families in rural or underserved areas, who may need to travel over 100 miles to receive care. These distances can delay diagnosis, disrupt continuity of treatment, and reduce participation in clinical trials [34]. At the same time, socioeconomic burden further compounds these challenges. Prolonged treatment durations, particularly for conditions such as acute lymphoblastic leukemia, which may extend for two to three years, place significant financial strain on families [35,36]. Costs related to transportation, temporary housing, and lost income can limit care continuity. Survivors also face increased long-term health risks, including a markedly higher likelihood of developing secondary malignancies, underscoring the need for sustained follow-up and survivorship care due to several opportunistic infections [37].

In addition to structural and economic factors, biological and communication-related challenges also influence pediatric cancer outcomes. Genetic predisposition syndromes, such as RB1 mutations, Li–Fraumeni syndrome, and neurofibromatosis type 1, contribute to cancer risk, while treatment-related exposures may increase the likelihood of secondary malignancies later in life [38]. At the same time, communication barriers and limited health literacy can affect how families understand and manage complex treatment protocols, which often involve multiple phases of therapy and long-term care requirements [39,40]. Language differences and gaps in understanding may reduce treatment adherence and engagement with healthcare providers. Together, these findings indicate that barriers to pediatric cancer care are multifactorial and interconnected, requiring coordinated strategies that address healthcare system limitations, socioeconomic disparities, geographic access, and communication challenges. Strengthening these areas will be essential for improving equitable access to diagnosis, treatment, and survivorship care in pediatric oncology [41].

5. Conclusion and Recommendations

5.1 Conclusion

In summary, this study highlights the complex and interconnected barriers that influence access to pediatric cancer care among underserved populations. Structural limitations within healthcare systems, socioeconomic challenges faced by families, geographic distance to specialized oncology centers, and communication barriers collectively affect timely diagnosis, treatment initiation, and continuity of care for children with cancer. Although substantial advances in pediatric oncology have improved survival outcomes in high-income countries, these benefits are not experienced equally across all communities. Addressing disparities in pediatric cancer care will require coordinated efforts that strengthen referral systems, expand access to specialized oncology services, and provide supportive resources for families navigating long-term cancer treatment. Future research should focus on population-based investigations and health system interventions that identify vulnerable populations and evaluate strategies aimed at improving equitable access to pediatric oncology care and survivorship services.

5.2 Recommendations

Future research should focus on developing more comprehensive population-based studies that examine how social determinants of health interact with clinical care delivery in pediatric oncology. Large datasets, such as national cancer registries and health services databases, could help identify vulnerable populations and quantify disparities in access to diagnosis, treatment, and survivorship care. In addition, multidisciplinary approaches that integrate clinical, genomic, and health system data may improve understanding of how biological risk factors and structural barriers jointly influence outcomes in childhood cancer. Policy-oriented research evaluating interventions such as regional oncology networks, telemedicine-supported referral systems, patient navigation programs, and financial assistance initiatives will also be important for identifying strategies that can reduce disparities and improve equitable access to pediatric cancer care.

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