

Bridging the Gap: Enhancing the Survival and Quality of Life for Children with Rare Cancer in Sub-Saharan Africa

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Childhood cancers, especially rare forms like Hodgkin's Lymphoma, Rhabdomyosarcoma, and Ewing's Sarcoma, present significant challenges in sub-Saharan Africa due to limited healthcare infrastructure, delayed diagnoses, and socio-economic barriers. Survival rates in sub-Saharan Africa are markedly lower than those in high-income countries. For example, Hodgkin's Lymphoma boasts a five-year survival rate of over 90% in high-income regions, compared to as low as 50% in sub-Saharan Africa. Rhabdomyosarcoma's survival rate exceeds 70% with optimal treatment in developed nations but remains under 30% in many parts of Africa. Similarly, Ewing's Sarcoma survival rates, which approach 60% in wealthier countries, are significantly lower due to late diagnoses and inadequate treatment facilities in this region. This review discusses the region's epidemiology, diagnostic obstacles, treatment barriers, and survival outcomes associated with these cancers. Highlighting disparities in care, the paper offers strategic recommendations, including improving healthcare infrastructure, enhancing training, establishing better cancer registries, and fostering international collaborations to enhance the survival and quality of life for affected children.

Keywords: Childhood Cancer, Hodgkin's Lymphoma, Ewing's Sarcoma, Rhabdomyosarcoma, Sub-Saharan Africa

Introduction

Childhood cancer poses a significant public health challenge globally, with severe impacts in sub-Saharan Africa due to socio-economic and healthcare limitations. While cancers like retinoblastoma and neuroblastoma are well-studied, rare cancers such as Hodgkin's Lymphoma, Rhabdomyosarcoma, and Ewing's Sarcoma lack sufficient research and understanding in this region. Limited epidemiological data and inadequate healthcare infrastructure lead to late diagnoses and poor survival rates (Stefan & Lutchman, 2014)¹. The region's unique socio-economic challenges compound these issues. Hodgkin's Lymphoma, originating from the lymphatic system, is rare compared to non-Hodgkin lymphomas in sub-Saharan Africa (Gupta et al., 2014)². Rhabdomyosarcoma, forming in soft tissues, and Ewing's Sarcoma, occurring in bones or surrounding soft tissue, present significant diagnostic and treatment challenges (Ward et al., 2014)³. The survival rates for these cancers are notably lower in sub-Saharan Africa than in high-income countries, emphasizing the need for targeted interventions (Ngoma et al., 2019)⁴. Disparities in cancer care are worsened by limited access to diagnostic tools and treatments, a shortage of trained healthcare professionals, and financial barriers (Ameh et al., 2012)⁵. Addressing these gaps is crucial for improving patient outcomes.

Additionally, the lack of comprehensive cancer registries impedes understanding the disease burden and developing effective

strategies (Sserunjogi et al., 2020)⁶. This research paper explores the epidemiology, diagnostic challenges, treatment barriers, and survival outcomes of Hodgkin's Lymphoma, Rhabdomyosarcoma, and Ewing's Sarcoma in sub-Saharan Africa. Having done this, we offer tentative solutions for improved healthcare strategies and international collaboration, which can enhance patient outcomes.

Overview of Rare Childhood Cancers

Hodgkin's Lymphoma, Rhabdomyosarcoma, and Ewing's Sarcoma are rare but significant forms of childhood cancers, each with unique characteristics and challenges in diagnosis and treatment. Hodgkin's Lymphoma originates in the lymphatic system, specifically in lymph nodes, and is characterized by the presence of Reed-Sternberg cells. The disease often presents as painless swelling in lymph nodes, particularly in the neck, underarms, or groin. Symptoms can also include unexplained fever, night sweats, weight loss, and fatigue. Diagnosis relies on lymph node biopsy and immunophenotyping, which identifies the Reed-Sternberg cells. Treatments typically involve chemotherapy and radiotherapy, with high survival rates in developed countries due to early detection and advanced treatment protocols (Ward et al., 2014)³.

Rhabdomyosarcoma is a malignant tumor arising from skeletal muscle progenitors, often occurring in the head, neck, or urogenital tract. It is the most common soft tissue sarcoma in

children. Symptoms depend on the tumor's location; for instance, tumors in the head or neck may cause swelling or vision problems, while urogenital tumors might lead to urinary difficulties or bleeding. Diagnosis involves imaging studies like MRI or CT scans, followed by biopsy to confirm malignancy. Multimodal treatment, a combination of surgery, chemotherapy, and radiotherapy, is the standard approach, but outcomes are poor in sub-Saharan Africa due to delays in diagnosis and limited access to comprehensive care (Ngoma et al., 2019)⁴.

Ewing's Sarcoma is a highly aggressive cancer that originates in bones or the surrounding soft tissues, most commonly affecting the pelvis, femur, and ribs. Patients often present with localized pain, swelling, and sometimes fever or fatigue. Advanced imaging techniques, including X-rays, MRI, and CT scans, alongside genetic testing to identify specific translocations (e.g., EWSR1-FLI1), are essential for diagnosis. Treatment typically includes chemotherapy, surgical resection, and radiotherapy. While survival rates can reach 60% in high-income settings, outcomes in sub-Saharan Africa are significantly poorer due to late diagnoses and limited access to specialized care (Gupta et al., 2014)². These cancers require timely and accurate diagnosis, specialized treatment, and multidisciplinary care, all of which are often lacking in sub-Saharan Africa. Addressing these gaps is critical to improving survival rates and quality of life for affected children.

Epidemiology of Rare Childhood Cancers in Sub-Saharan Africa

The epidemiology of rare childhood cancers in sub-Saharan Africa reveals stark disparities compared to global trends. Hodgkin's Lymphoma, for example, has an incidence rate in Uganda's registry of approximately 3 per 100,000 children annually, significantly lower than in high-income countries where rates exceed 10 per 100,000 due to earlier detection and better diagnostic tools (Musaazi et al., 2017)⁷. In Kenya, similar patterns emerge, with over 60% of cases diagnosed at advanced stages (Korir et al., 2015)⁸. Rhabdomyosarcoma, while rare globally, is notably underreported in sub-Saharan Africa, with an estimated annual rate of 1.2 per 100,000 children, often diagnosed too late for effective intervention. Ewing's Sarcoma presents equally concerning statistics, with South African studies indicating a prevalence of 1.1 per 100,000 children and survival rates falling below 20% due to inadequate therapeutic options (Ngoma et al., 2019)⁴. These figures highlight the urgent need for comprehensive cancer registries and epidemiological studies across the region to inform effective interventions and resource allocation. Visual representations of these trends, such as geographic distribution maps and incidence graphs, could further emphasize disparities.

Survival Outcomes and Quality of Life

Survival outcomes for children diagnosed with rare cancers such as Hodgkin's Lymphoma, Rhabdomyosarcoma, and Ewing's Sarcoma in sub-Saharan Africa are markedly poorer compared to those in high-income countries. This discrepancy is primarily due to late-stage diagnoses, limited access to appropriate treatments, and various socioeconomic barriers (Gupta et al., 2014)². Understanding and addressing these issues is critical for improving both survival rates and the overall quality of life for these young patients.

A. Analysis of Survival Rates

The survival rates for childhood cancers in sub-Saharan Africa are significantly lower than those observed in more developed regions. Studies have shown that the five-year survival rate for Hodgkin's Lymphoma can exceed 90% in high-income countries. In sub-Saharan Africa, it can be as low as 50% due to delayed diagnoses and inadequate treatment (Stefan & Lutchman, 2014)¹. Similarly, the survival rates for rhabdomyosarcoma and Ewing's sarcoma are considerably lower in this region. For instance, while the survival rate for Rhabdomyosarcoma can reach up to 70% with optimal treatment, it drops dramatically in sub-Saharan Africa due to the lack of comprehensive cancer care facilities (Ngoma et al., 2019)⁴.

B. Factors Influencing Survival Outcomes

Several factors contribute to the poor survival outcomes for children with rare cancers in sub-Saharan Africa:

1. **Stage at Diagnosis:** Many children are diagnosed at an advanced stage of the disease, significantly reducing the effectiveness of treatment options and overall survival rates (Ameh et al., 2012)⁵.
2. **Access to Treatment:** The availability and quality of cancer treatment are inconsistent across the region. Many healthcare facilities lack the necessary resources to provide effective chemotherapy, radiation therapy, and surgical interventions (Ward et al., 2014)³. **Supportive Care and Follow-Up:** Post-treatment supportive care, which is crucial for managing side effects and preventing recurrence, is often inadequate. Follow-up care is hindered by logistical challenges and a shortage of healthcare professionals trained in pediatric oncology (Ribeiro et al., 2008)¹⁰.

C. Long-Term Health and Quality of Life for Survivors

For those children who do survive, their long-term health and quality of life can be severely impacted. Survivors of childhood cancers often face chronic health issues, including physical disabilities, cognitive impairments, and

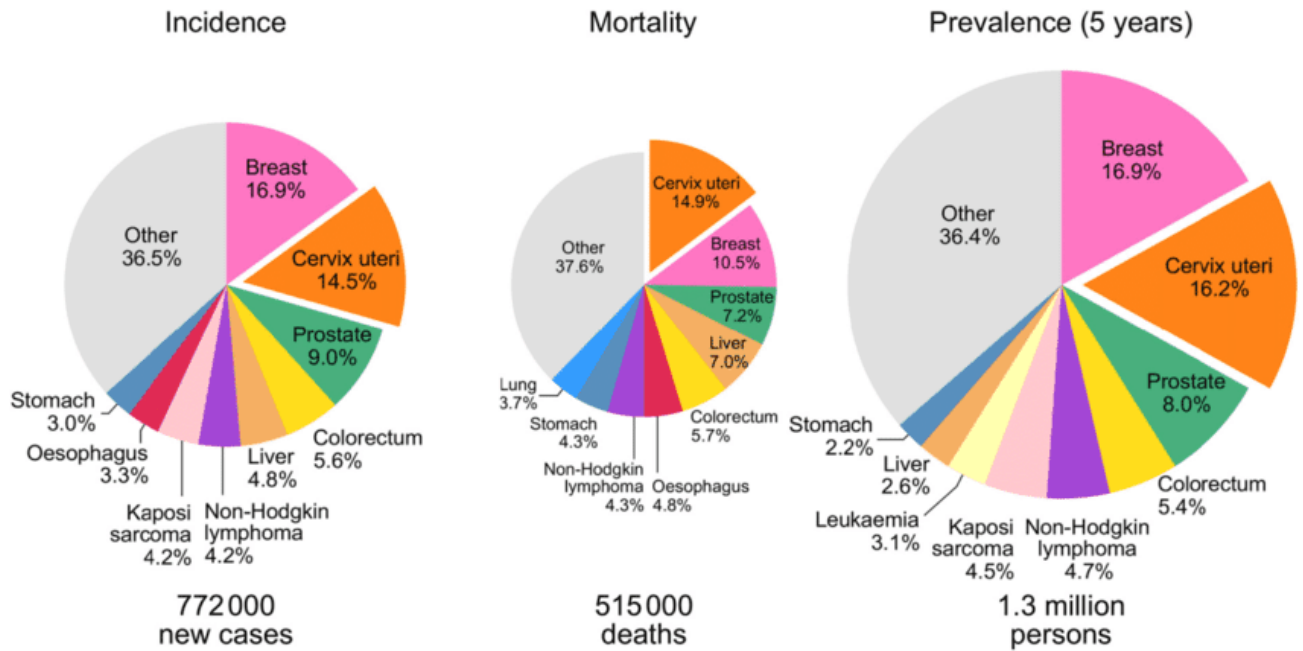


Fig. 1 This figure shows the incidence rate of cancer in Sub-Saharan Africa. (Ferlay et al., 2018b)⁹

secondary malignancies. The psychological and social impacts are also profound, with many children experiencing anxiety, depression, and social isolation as a result of their illness and treatment (Stefan & Lutchman, 2014)¹. Socio-economic factors further compromise the quality of life. Families often face significant financial burdens due to the cost of cancer treatment, which can lead to poverty and limit access to education and other essential services for the child (Ngoma et al., 2019)⁴. Additionally, as mentioned earlier, the stigma associated with cancer in some communities can lead to discrimination and social exclusion, exacerbating the challenges faced by survivors (Sserunjogi et al., 2020)⁴.

D. Psychological and Social Impacts on Patients and Families

The psychological and social impacts of childhood cancer extend beyond the patients to their families. Parents and siblings often experience high levels of stress, anxiety, and depression due to the emotional and financial strain of dealing with the illness. The need for ongoing care and support can disrupt family dynamics and strain relationships (Ameh et al., 2012)⁵. Addressing these issues requires a holistic approach that includes not only medical treatment but also psychological and social support for both patients and their families. Integrating psychosocial services into pediatric oncology care can help mitigate the long-term impacts of cancer and improve the overall quality of life for survivors (World Health Organization, 2021)¹¹. As such, the sur-

vival outcomes and quality of life for children with rare cancers in sub-Saharan Africa are influenced by a complex interplay of medical, socio-economic, and psychological factors.

Diagnostic Challenges

Diagnosing rare childhood cancers in sub-Saharan Africa faces systemic and resource-based hurdles. Infrastructure deficits are critical, with fewer than 30% of healthcare facilities equipped with advanced imaging technologies like MRI and PET scans. These limitations result in frequent misdiagnoses and delays, reducing treatment efficacy (Ward et al., 2014)³. Histopathology and genetic testing, key for accurate cancer identification, are only available in a minority of regional hospitals, compounding the issue (Ribeiro et al., 2008)¹⁰. The shortage of trained healthcare professionals further exacerbates diagnostic delays, with many lacking the expertise to recognize early-stage symptoms of these rare cancers (Ameh et al., 2012)⁵. Additionally, socio-economic factors and cultural beliefs often delay healthcare-seeking behavior. Families might consult traditional healers first or avoid hospitals due to the stigma associated with cancer diagnoses (Stefan & Lutchman, 2014)¹.

Addressing these diagnostic challenges requires a broad set of initiatives. Improving healthcare infrastructure and access to diagnostic tools is essential. Training programs for healthcare professionals can enhance their ability to recognize and diagnose rare cancers early. Additionally, public health campaigns

can raise awareness about cancer symptoms and the importance of early diagnosis (World Health Organization, 2021)¹¹. Innovative approaches such as mobile diagnostic units and telemedicine can also help bridge the gap in access to specialized diagnostic services. International collaborations and partnerships can provide technical support, funding, and training to improve diagnostic capabilities in sub-Saharan Africa (Ngoma et al., 2019)⁴. Overcoming these barriers requires comprehensive efforts to improve healthcare infrastructure, enhance training for healthcare professionals, and address socio-economic and cultural factors that contribute to delays in diagnosis. By tackling these challenges, it becomes possible to improve early diagnosis and treatment outcomes for children with rare cancers in the region. Such advancements are crucial for giving these children a better chance at survival and a higher quality of life.

Treatment Barriers

Treatment for childhood cancers in sub-Saharan Africa is hindered by a lack of resources, financial burdens, and logistical challenges. Standard treatment protocols for these cancers typically involve a combination of chemotherapy, surgery, and radiation therapy. However, the availability of these treatments in sub-Saharan Africa is often limited. Many healthcare facilities lack the necessary equipment for radiation therapy, and there is a shortage of oncologists and specialized surgeons capable of performing the complex procedures required for these cancers (Gupta et al., 2014)². For instance, effective treatment of Rhabdomyosarcoma and Ewing's Sarcoma often requires multimodal therapy, including surgical resection of tumors, which is challenging to provide consistently in resource-limited settings (Stefan & Lutchman, 2014)¹. In Kenya, despite advancements, many facilities still struggle with these limitations, affecting treatment outcomes (Korir et al., 2015)⁸. This limitation significantly impacts the chances of successful treatment and survival. Financial barriers are also significant. The cost of cancer treatment is prohibitively high for many families in sub-Saharan Africa. Even when public healthcare systems provide some level of care, the additional costs of medications, transportation, and supportive care can be overwhelming. Many families face the difficult choice of prioritizing basic needs over expensive cancer treatments, leading to treatment abandonment or non-compliance with medical recommendations (Ngoma et al., 2019)⁴. In Uganda, the financial burden of cancer treatment remains a major hurdle, often forcing families to seek help from NGOs (Mutuyaba et al., 2013)¹². This financial strain affects not only the immediate treatment but also long-term follow-up and overall health outcomes for the children.

Logistical challenges further complicate treatment access. The long distances that patients often need to travel to reach specialized cancer treatment centers can delay the start of therapy and interrupt ongoing treatment schedules. Poor transportation

infrastructure and the absence of reliable referral systems exacerbate these issues, making consistent follow-up and continuity of care difficult (Ward et al., 2014)³. In Rwanda, despite improvements, logistical issues still pose significant barriers to effective cancer care (Brierley et al., 2017)¹³. These logistical hurdles create additional stress for families and can lead to inconsistent treatment, reducing the efficacy of the therapies administered.

Case Studies

These malignancies often occur in healthcare settings where access to advanced diagnostics and specialized care is limited. Examining such cases helps gain deeper insights into the systemic obstacles and potential pathways for improvement in managing rare diseases in children, particularly in resource-constrained environments like sub-Saharan Africa. For example, Ewing Sarcoma, as observed in a 17-year-old female athlete (Ozobokeme et al., 2022)¹⁴, highlights the critical role of early molecular diagnostics. The patient presented with characteristic symptoms, including localized pain and swelling. Despite its aggressive nature, advanced diagnostic tools like FISH and immunohistochemistry enabled precise identification, while a multidisciplinary treatment approach incorporating chemotherapy, surgery, and radiotherapy improved her prognosis. This case underscores the importance of timely access to sophisticated diagnostic facilities, an area often deficient in sub-Saharan Africa, where many children present with advanced disease stages due to delayed recognition.

In the Democratic Republic of Congo, a neonatal nephroblastoma case (Matondo et al., 2015)¹⁵ reflects the challenges of cancer management in resource-constrained settings. This rare tumor was diagnosed late, following visible abdominal distension, due to the absence of prenatal imaging and limited healthcare infrastructure. The neonate underwent surgery but lacked access to adjunctive therapies like chemotherapy or radiotherapy, ultimately leading to a fatal outcome. This case starkly illustrates how infrastructural deficits and delayed interventions exacerbate survival disparities in sub-Saharan Africa, emphasizing the need for comprehensive prenatal care and pediatric oncology services. The diagnosis of alveolar rhabdomyosarcoma in a 10-year-old girl from Tunisia (Mekni et al., 2004)¹⁶ highlights the challenges of recognizing atypical cancer presentations. This aggressive variant, marked by significant lymph node involvement, required advanced diagnostic evaluations, including histopathology and immunohistochemistry. Despite multimodal treatment, including chemotherapy and radiotherapy, the advanced stage at diagnosis limited the effectiveness of interventions. Similar challenges are prevalent in sub-Saharan Africa, where limited oncology expertise and resources often delay treatment initiation for children with complex malignancies.

These case studies collectively underscore the systemic gaps in pediatric oncology care across various settings, particularly

in sub-Saharan Africa. The reliance on advanced diagnostic and therapeutic modalities in high-resource settings contrasts sharply with the limited capabilities in resource-constrained regions. As illustrated in these narratives, delays in diagnosis, limited treatment options, and inadequate healthcare infrastructure perpetuate survival disparities for rare pediatric cancers. Hence, addressing these systemic barriers will allow healthcare systems can move toward equitable access to oncology care for children, irrespective of geographic or socio-economic limitations, particularly in Africa. From the necessity of timely molecular diagnostics to the critical importance of prenatal imaging and oncological expertise, these cases reinforce the essay's central themes. Improving healthcare infrastructure, providing training for specialized care teams, and fostering global collaborations are pivotal for addressing the challenges these cases reveal. These narratives draw parallels between the case-specific obstacles and broader systemic issues, helping advocate for targeted interventions that could dramatically improve outcomes for children with rare cancers in sub-Saharan Africa and beyond.

Comparative Analysis of Childhood Cancer Outcomes Across Regions

Childhood cancer outcomes vary significantly across regions, shaped by disparities in healthcare infrastructure, access to advanced diagnostics, and availability of multidisciplinary care. A comparative analysis between high-income countries (HICs) and sub-Saharan Africa (SSA) highlights stark contrasts in survival rates, intervention efficacy, and healthcare delivery systems. These disparities underline the critical need for targeted interventions to improve care and outcomes. In HICs, such as the United States and Western Europe, survival rates for pediatric cancers like Wilms' tumor exceed 90%, attributed to early diagnosis and comprehensive treatment protocols (Matondo et al., 2015)¹⁵. Robust healthcare systems in these regions provide consistent access to advanced diagnostic tools, such as fluorescence in situ hybridization, immunohistochemistry, and genomic profiling. These tools enable early detection and precise classification of malignancies, leading to timely and effective treatment (Smith et al., 2021)¹⁷. In SSA, however, survival rates often fall below 50% for the same cancers due to late-stage presentation, misdiagnosis, and lack of diagnostic capabilities (Matondo et al., 2015)¹⁵. For example, the neonatal nephroblastoma case highlights the challenges of diagnosing complex tumors without advanced imaging and histopathological tools, common limitations in SSA healthcare settings.

Diagnostic delays also exacerbate outcomes in cases of rhabdomyosarcoma, where atypical presentations lead to frequent misdiagnoses as infections or benign conditions (Mekni et al., 2004)¹⁶. Studies indicate that in many SSA regions, over 70% of childhood cancer cases are diagnosed at advanced stages, sig-

nificantly reducing survival prospects (WHO, 2020)¹⁸. Strengthening diagnostic infrastructure and training healthcare providers to recognize early cancer symptoms are essential for bridging this gap. HICs benefit from established treatment protocols, including tailored chemotherapy regimens, advanced radiotherapy, and access to surgical expertise. For instance, the standard chemotherapy regimens for Wilms' tumor and rhabdomyosarcoma have shown significant survival improvements when paired with surgical intervention and radiotherapy (Mekni et al., 2004)¹⁶. Additionally, HICs have access to innovative treatments, such as targeted therapies and immunotherapy, which have further improved survival rates in specific cancers (Johnson et al., 2019)¹⁹. In SSA, limited access to these therapies results in incomplete treatment cycles and higher mortality rates. The neonatal nephroblastoma case illustrates how the absence of chemotherapy and radiotherapy options significantly impacts outcomes (Matondo et al., 2015)¹⁵. Similarly, while Tunisia offers multimodal treatment for rhabdomyosarcoma, late-stage diagnosis often undermines its efficacy (Mekni et al., 2004)¹⁶. Research shows that less than 30% of children with cancer in SSA receive complete treatment due to financial constraints, lack of infrastructure, and logistical barriers, including long travel distances to healthcare facilities (Stefan et al., 2014)¹.

HICs have demonstrated the effectiveness of comprehensive cancer care models. Multidisciplinary teams (MDTs) integrating oncologists, pathologists, and radiologists enable early diagnosis and coordinated treatment planning. Survivorship programs, such as those in the United States, provide long-term follow-up care to mitigate late effects and monitor for secondary malignancies (Ward et al., 2014)¹. Innovations in pediatric oncology, including precision medicine and personalized treatment plans, have further enhanced survival rates and quality of life for survivors (Johnson et al., 2019)¹⁹. Despite systemic challenges, some SSA countries have initiated programs demonstrating promising results. Uganda's partnership with international organizations to establish pediatric oncology units has reduced diagnostic delays and improved survival rates for common childhood cancers by up to 30% (WHO, 2020)¹⁸. Kenya's pilot cancer registry programs have facilitated better resource allocation and planning for pediatric oncology services, emphasizing the importance of accurate data in guiding healthcare interventions (Stefan et al., 2014). Training programs for healthcare providers in SSA, supported by global collaborations, are beginning to address systemic bottlenecks. Regional centers of excellence, such as the Uganda Cancer Institute, are increasingly offering comprehensive care, including chemotherapy and palliative services, albeit on a limited scale. These efforts highlight the potential for scaling successful models through sustained investments and international support.

Cultural Variations

Cultural factors, along with the regional disparities significantly influence healthcare-seeking behavior and outcomes in sub-Saharan Africa. In Nigeria, for instance, widespread reliance on traditional healers delays medical intervention, with studies showing that 30% of families consult alternative practitioners before seeking hospital care (Ngoma et al., 2019). Ethiopia's rural regions face unique challenges, where healthcare facilities are inaccessible and awareness campaigns are sparse, resulting in late-stage cancer presentations. Urban-rural disparities in South Africa exacerbate inequities, as urban children are three times more likely to receive timely diagnoses and treatment compared to their rural counterparts (Stefan & Lutchman, 2014)¹. In addition to these disparities, cultural beliefs about cancer often lead to delays in care. In many communities, cancer is seen as a fatal or spiritual disease, discouraging families from seeking medical attention. Public health initiatives aimed at changing these perceptions have had varying success. For example, a community outreach program in Uganda that included traditional healers in awareness campaigns saw a 20% increase in early cancer diagnoses (WHO, 2020)¹⁸. However, scaling such initiatives remains a challenge due to funding constraints and logistical complexities.

Here, geographic disparities also play a significant role. Countries like Rwanda have made progress in improving healthcare access through community health worker programs, while larger countries like Nigeria continue to struggle with uneven healthcare distribution. Comparatively, South Africa's centralized urban healthcare model has achieved success in urban areas but leaves rural populations at a disadvantage (Matondo et al., 2015)¹⁵. Addressing these disparities requires not only infrastructural investments but also culturally sensitive strategies that engage local communities and address barriers to care.

Policy and Healthcare Strategy Recommendations

One of the most critical steps is to improve the healthcare infrastructure across sub-Saharan Africa. This involves ensuring that healthcare facilities are equipped with the necessary diagnostic and treatment tools, including advanced imaging equipment, pathology labs, and radiotherapy units (Gupta et al., 2014)². For instance, Kenya has made strides in this area by establishing the Kenyatta National Hospital as a regional cancer treatment center equipped with advanced radiotherapy units and a well-resourced pathology lab (Korir et al., 2015)⁸. Similarly, Uganda's Uganda Cancer Institute has been pivotal in providing specialized oncology services and conducting cancer research, supported by partnerships with international organizations like the Fred Hutchinson Cancer Research Center (Nakaganda et al., 2024)⁸. Rwanda, though still developing its cancer care infrastructure, has begun equipping its hospitals with essential

diagnostic tools and has plans to establish a national cancer center (Brierley et al., 2017)¹³. By learning from these countries' experiences, other regions can adopt similar models to enhance their healthcare infrastructure and improve patient outcomes.

Training and continuous education for healthcare professionals are also paramount for improving cancer care. Developing and implementing training programs for doctors, nurses, and support staff in pediatric oncology can improve diagnostic accuracy and treatment efficacy (Ward et al., 2014)³. Kenya's partnership with international institutions has led to the creation of specialized training programs in pediatric oncology, enhancing the skills of healthcare providers (Korir et al., 2015)⁸. Uganda has also benefited from training programs supported by the American Society of Clinical Oncology, which have significantly improved the capacity of its healthcare professionals (Nakaganda et al., 2024)²⁰. Offering ongoing education and professional development opportunities ensures that healthcare providers stay updated on the latest advancements in cancer treatment and care (Ameh et al., 2012)⁵. Creating fellowships and exchange programs with institutions in high-income countries can allow healthcare professionals from sub-Saharan Africa to gain hands-on experience and training (Ribeiro et al., 2008)¹⁰. These initiatives are crucial for building a robust, well-informed workforce capable of addressing the unique challenges posed by rare childhood cancers.

Addressing Systemic Barriers in Cancer Data Collection

Accurate data collection is essential for understanding the burden of rare childhood cancers and planning effective interventions. Developing national and regional cancer registries to collect detailed information on cancer incidence, treatment, and outcomes is crucial (Sserunjogi et al., 2020)⁶. Implementing standardized data collection methods ensures consistency and reliability of the data across different regions (World Health Organization, 2021)¹¹. Kenya has established a robust national cancer registry that tracks cancer incidence and outcomes, providing critical data for public health planning (Korir et al., 2015)⁸. Uganda's cancer registry, supported by international collaborations, has also been effective in monitoring cancer trends and informing healthcare strategies (Musaaazi et al., 2017)⁷. Utilizing registry data can inform public health policies, allocate resources efficiently, and identify areas needing intervention (Gupta et al., 2014)². The success of these registries underscores the importance of accurate data in combating childhood cancers and improving treatment outcomes.

In addressing these diagnostic challenges, one of the main avenues is to leverage digital technologies to address data collection issues. The lack of comprehensive cancer data in sub-Saharan Africa is a multidimensional problem rooted in sys-

temic inefficiencies, resource constraints, and infrastructural gaps. Digital health technologies hold transformative potential for addressing data collection challenges. Mobile-based platforms, such as the CanReg5 software developed by the International Agency for Research on Cancer (IARC), allow for streamlined data entry, reducing reliance on error-prone, paper-based systems (Korir et al., 2015)⁸. Through real-time data collection and automated reporting, these systems can significantly improve the accuracy and timeliness of cancer registries. Recent initiatives in Kenya and South Africa have demonstrated that integrating CanReg5 with hospital electronic medical records leads to improved data harmonization and reduced reporting lags (Musaazi et al., 2017)⁷. Moreover, cloud-based solutions can facilitate cross-regional data sharing and analysis, crucial for understanding cancer trends in resource-limited settings.

A major pitfall of earlier registry programs has been their reliance on short-term international funding. To ensure sustainability, governments must prioritize cancer registry development within national budgets. Public-private partnerships provide a viable pathway for securing long-term funding and technical expertise. For example, in Kenya, collaboration between the Ministry of Health, American Cancer Society, and Roche Pharmaceuticals has led to the establishment of pilot cancer registry programs that are gradually scaling up to cover the entire country (Ngoma et al., 2019). These partnerships also offer avenues for capacity building, including training local healthcare workers in data management and cancer surveillance. Enforcing mandatory cancer reporting laws is another critical step toward ensuring comprehensive data collection. Countries like Rwanda and Uganda have successfully implemented legislation requiring healthcare facilities to report all cancer cases to a central registry (Musaazi et al., 2017)⁷. These legal frameworks must be accompanied by robust monitoring mechanisms to ensure compliance and address underreporting from private and rural healthcare providers. Additionally, policies should incentivize reporting through financial or logistical support, particularly for under-resourced clinics and hospitals.

Building Human Capacity

Effective cancer registries require skilled personnel to manage data collection, analysis, and reporting. Training programs should be institutionalized, offering certifications in cancer registration and epidemiology. Partnerships with international organizations such as the Union for International Cancer Control and IARC can facilitate knowledge exchange and provide access to training resources. For example, the African Cancer Registry Network has been instrumental in training healthcare workers in advanced registry management techniques, significantly improving data quality in member countries (Korir et al., 2015)⁸. Community-level barriers, such as stigma, mistrust, and lack of awareness, also hinder data collection efforts. Public awareness

campaigns are essential for educating communities about the importance of cancer data and encouraging families to participate in data collection processes. Cultural sensitivity is crucial for the success of these campaigns. For instance, integrating local languages and traditional healers into awareness programs can build trust and improve community engagement. In Ethiopia, such culturally tailored approaches have led to increased community participation in healthcare initiatives (Ngoma et al., 2019)⁴. The success of these registry improvements can be ensured by establishing regular monitoring and evaluation mechanisms. Key performance indicators such as data completeness, timeliness, and quality, should be tracked and reported annually. Independent audits can provide additional oversight, identifying areas for improvement and ensuring accountability. Countries like Botswana have implemented such practices, leading to measurable improvements in registry performance over a five-year period (Stefan & Lutchman, 2014)¹. Combining these advance technologies with sustainable funding models backed by community engagement can aid these proposed strategies to dress entrenched deficiencies that have historically impeded cancer registry development in sub-Saharan Africa. These measures must be implemented within a coordinated, region-wide framework to ensure their success, ultimately enabling data-driven interventions that improve cancer outcomes for children in the region.

International Collaboration

International partnerships have demonstrated significant potential in improving pediatric oncology outcomes in sub-Saharan Africa. Programs like My Child Matters, which provides funding and technical support to local oncology units, have facilitated the establishment of treatment protocols and improved survival rates by up to 30% in participating countries (Ribeiro et al., 2008)¹⁰. The Fred Hutchinson Cancer Research Center's collaboration with the Uganda Cancer Institute has bolstered diagnostic capabilities and professional training, resulting in a 20% reduction in diagnostic delays (Nakaganda et al., 2024)²⁰. Expanding these collaborations to include advanced technologies like artificial intelligence for diagnostics and telemedicine for treatment planning could further enhance healthcare delivery. Sustainability, however, must remain a focus, emphasizing the training of local professionals and the integration of new technologies into national healthcare systems to ensure long-term success. Including case studies of successful collaborations and their quantitative impacts would enrich this section.

Conclusion

It is apparent that the challenges faced by children diagnosed with rare cancers such as Hodgkin's Lymphoma, Rhabdomyosar-

coma, and Ewing's Sarcoma in sub-Saharan Africa are severe. These children are often diagnosed late, suffer from limited access to advanced diagnostic and treatment facilities, and face significant socio-economic barriers. The survival outcomes and quality of life for these patients starkly contrast with those in high-income countries, emphasizing the urgent need for systemic improvements. To bridge this gap, a comprehensive approach is necessary. Strengthening healthcare infrastructure, enhancing training for healthcare professionals, and establishing comprehensive cancer registries are critical steps. Public health campaigns to raise awareness about early cancer detection and international collaborations to provide resources and expertise are equally vital. Innovative solutions, such as telemedicine and mobile clinics, can also play a significant role in bringing specialized care to remote areas. As such, improving the prognosis and quality of life for children with rare cancers in sub-Saharan Africa requires a unified commitment from governments, international organizations, and local communities. Only through sustained and collaborative efforts can we hope to give these children a chance for a better future, free from the shadows of inadequate healthcare and socio-economic disparities. The journey ahead is long, but with dedication and concerted action, significant progress can be made in the fight against childhood cancers in this region.

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